Investigation of oral health assessment measures for the care planning of dependent adults

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Doctor of Philosophy Thesis

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Newcastle University

April 2021

Abstract

Dependent adults (i.e. eighteen-year-old or older who need or receives assistance due to a reduction in mental capacity or physical capability) can experience oral health problems. Whilst the reasons behind these problems are complex, evidence suggests that caregivers' limited knowledge about oral health and care may play a role. Oral health measurement instruments could provide one means by which to help caregivers establishing appropriate oral care plans for dependent adults and, thus, preventing or managing these problems. This project aimed to investigate oral health assessment measures for oral care planning of dependent adults through three separate studies.

A qualitative evidence synthesis was undertaken to establish an empirical conceptual model of oral health in dependent adults. It showed that oral health in dependent adults is a dynamic and multidimensional construct that consists of four domains: the intactness and cleanliness of oral structures; oral pain and discomfort; oral functions; and noticeable oral health aspects.

A systematic review was undertaken to critically appraise published oral health measurement instruments for dependent adults. It revealed many instruments have been proposed, but none of these instruments has been adequately and comprehensively tested to establish strong evidence in relation to their measurement properties, feasibility and interpretability.

Finally, a qualitative interview study was undertaken to explore healthcare service providers' perspectives on barriers and implementation issues in relation to measuring oral health in dependent adults. The consistent theme was that the implementation of oral health measurement instruments may not be easy due to multiple potential barriers. These barriers therefore need to be considered during implementation, including those related to instruments, service providers, dependent adults and implementation environment.

The findings in this thesis support a recommendation that multiple perspectives need to be considered when designing and evaluating oral health measurement instruments used to guide oral care planning for dependent adults. By doing this, these instruments are more likely to meet different stakeholders' needs and, thus, can be successfully implemented.

Dedication

This thesis is dedicated to my beloved family.

Acknowledgements

All praise is due to *Allah* the Almighty for the graces He has bestowed upon me and for the strength and patience that He granted me to pursue and undertake my study. Without His mercy and help, none of this work would have been accomplished.

I was fortunate to work under the supervision of great academics. I would like to offer my sincere and heartfelt thanks to Professor Giles McCracken for his enthusiasm, outstanding supervision, and thorough guidance throughout every step of this research project. I have been privileged to work with him, and I am very grateful for his constant support throughout my study journey. I wish to express my deep gratitude to Professor Justin Durham for his wise advice and invaluable feedback. I would also like to extend my thanks to Dr Rebecca Wassall and Dr Bana Abdulmohsen for their continuous help and support.

It is impossible to thank every one of those who gave me special assistance, encouragement, and advice along the way, but I owe a special debt of gratitude to the following people: Dr Margaret Stewart and Mr Jamal Akhil for their contributions to the systematic review studies; Dr Susan Bissett for helping me to secure the necessary approvals for the qualitative study; and Professor Helen Rodgers and Professor Craig Smith for helping me to identify and recruit participants for the qualitative study. I would like to acknowledge all of the participants in the qualitative study and thank them for providing their insight and experience. I also extend thanks to my friends and colleagues at Newcastle University for enriching the research through their intellectual advice and discussions.

I wish to acknowledge the trust and support of my Government, represented by King Saud bin Abdulaziz University for Health Sciences, in granting me a scholarship and sponsoring my study.

Last, but certainly not least, I am grateful to my whole family. My sincere gratitude goes to my parents for their unlimited support and prayers for me to achieve my goal. I cannot thank my beloved wife enough for her patience, support, and reassurance. I also extend my thanks to my sister and brothers for always being there for me when I needed them.

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List of Abbreviations

£	Pound sterling
<	Lesser than
>	More than
σ	Sigma
ADL	Activities of Daily Living
BA	Bana Abdulmohsen
BeHEMoTh	Behaviour of interest, Health context, Exclusions, and Models or Theories
BOHSE	Brief Oral Health Status Examination
CASP	Critical Appraisal Skills Programme
CENTRAL	Cochrane Central Register of Controlled Trials
COSMIN	Consensus-based Standards for the Selection of Health Measurement Instruments
DMFT	Decayed Missing Filled Teeth
ENTREQ	Transparency in Reporting the Synthesis of Qualitative Research
FACS	Facial Actions Coding System
FB	Fahad BaHammam
FDI	World Dental Federation
FMS-EC	Faculty of Medical Sciences-Ethics Committee
GM	Giles McCracken

GRADE	Grading of Recommendation Assessment, Development and Evaluation
GRADE-CERQual	Confidence in the Evidence from Reviews of Qualitative research
HRA	Health Research Authority
HTA	Health Technology Assessment
ICDAS	International Caries Detection and Assessment System
ICF	International Classification of Functioning, Disability and Health
JA	Jamal Akhil
MeSH	Medical Subject Headings
MOBID	Mobilization–Observation–Behaviour–Intensity–Dementia for mouth care
MPS	Mucosal-Plaque Score
MS	Margaret Stewart
N	Newcastle upon Tyne Hospitals NHS Foundation Trust
NHS	National Health Service
OAS	Oral Assessment Sheet
OATD	Open Access Theses and Dissertations
OHAT	Oral Health Assessment Tool
OHI	Oral Health Index
OHSTNP	Oral Health Screening Tool for Nursing Personnel
OPS-NVI	Orofacial Pain Scale for Non-Verbal Individuals

PCP	Patient and Carer Panel
PhD	Doctor of Philosophy
PICOS	Participants, Interventions, Comparators, Outcomes and Studies
P	Participant
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	The International Prospective Register of Systematic Reviews
ROAG	Revised Oral Assessment Guide
RW	Rebecca Wassall
S	Salford Royal NHS Foundation Trust
SLT	Speech and language therapist
SPIDER	Sample, Phenomena of Interest, Design, Evaluation and Research type
THROAT	The Holistic and Reliable Oral Assessment Tool
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Chapter 1. Introduction and Outline of the Thesis

1.1 Introduction

Dependent adults who are reliant on others for self-care have been reported to experience deterioration in their oral health (da Cruz *et al.*, 2014; Delwel *et al.*, 2017; Yoon *et al.*, 2018). In fact, these reports about oral health deterioration seem to represent a worldwide phenomenon (Marks *et al.*, 2015; Fernandez Rojas *et al.*, 2016; Yoon *et al.*, 2018). The association between being dependent and experiencing oral health decline appears to exist in adults with different causes of dependency (i.e. age-related, mental or physical), as well as different living settings (i.e. hospitals, care homes and the community) (Pow *et al.*, 2005; da Cruz *et al.*, 2014; Karki *et al.*, 2015; Petrovic *et al.*, 2016). Oral health conditions that have been reported to worsen in adults after becoming dependent include poor oral hygiene, halitosis, dental caries, gingivitis, periodontitis and severe dental infections (da Cruz *et al.*, 2014; Karki *et al.*, 2015). In addition, denture-related problems, such as ill-fitting dentures, poor denture hygiene and denture stomatitis, were also reported (Andersson *et al.*, 2017; Yoon *et al.*, 2018). Furthermore, dependent adults have been shown to experience several mucosal lesions such as angular cheilitis, a fissured tongue and mucosal ulcers (Fernandez Rojas *et al.*, 2016; Yoon *et al.*, 2018). In light of the above, it is unsurprising that dental pain in dependent adults is common, with 1 in 4 dependent adults being affected by it (Fernandez Rojas *et al.*, 2016; Yoon *et al.*, 2018; Delwel *et al.*, 2019).

One of the main contributing factors of oral health deterioration in dependent adults is the challenging nature of providing them with regular oral care by their caregivers (Göstemeyer *et al.*, 2019). Thus, barriers to providing adequate oral care for dependent adults have been extensively investigated (Göstemeyer *et al.*, 2019). In fact, there is a wide variety of barriers that have been reported, which are related to dependent adults themselves, their caregivers or their environments (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015). One of the most frequently identified barriers in the literature is the caregiver's lack of knowledge about oral health and oral care (Göstemeyer *et al.*, 2019). Indeed, professional and non-professional caregivers from different settings have voiced their insecurity regarding their dental knowledge (Reis *et al.*, 2011; Horne *et al.*, 2015). The lack of knowledge issue is mainly manifested in caregivers' inability to easily detect oral health problems in those who are dependent on them for personal care (De Visschere *et al.*, 2015; Horne *et al.*, 2015). It was also manifested in the caregivers not feeling able to undertake the right actions to resolve obvious oral health problems (De Visschere *et al.*, 2015; Horne *et al.*, 2015). These manifestations may explain why caregivers have clearly expressed a need for an oral health measurement instrument that could be used to guide oral care planning for dependent adults (Hijii, 2003; Horne *et al.*, 2015; Andersson *et al.*, 2019). While several oral health measurement instruments have been developed to address this need (Chalmers and Pearson, 2005), none of these instruments has been widely used in clinical practice. Thus, it might be necessary to critically appraise these instruments to identify their limitations, investigate the potential barriers that may prevent them for being used and explore how to overcome those limitations and barriers.

1.2 Outline of the Thesis

This PhD thesis consists of seven chapters. Following this introductory chapter, the second chapter reviews the contemporary literature surrounding the topics of oral health, dependency in adults and oral health in dependent adults. The third chapter states the aim, objectives and programme of work of this PhD project. The following three empirical chapters involve two systematic reviews and one qualitative interview study, which collectively investigate and explore the subject of assessing oral health in dependent adults to guide their oral care planning. The final chapter highlights the key findings of this PhD project and their implications on clinical practice and future research.

Chapter 2. Literature Review

2.1 Oral Health

2.1.1 Defining the concept of oral health

In 1946, the World Health Organisation (WHO) provided a radical and ground-breaking definition of health which is, to date, one of the most comprehensive definitions. It stated that "*Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity"* (WHO, 1946). This was the first attempt to comprehend the concept of health beyond the duality of health and disease and to emphasise the multidimensional nature of health. Nevertheless, the WHO definition has been criticised for being overambitious and not achievable in the real world (Huber *et al.*, 2011; Lee *et al.*, 2017a).

For almost 30 years after the WHO definition of health was proposed, the concept of oral health was still only viewed through a narrow disease model, which ignored patients' lived experience of their oral health (Bennadi and Reddy, 2013). It was only after Cohen and Jago (1976) advocated evaluating the other health axes in respect of oral health that a number of more comprehensive definitions of oral health were proposed by different researchers and health organisations (Dolan, 1993; US Department of Health and Human Services, 2000; Department of Health: Dental and Ophthalmic Services Division, 2005; ADA, 2014; WHO, no date). The definition that was stated by the Oral Health Strategy Group in the National Health Service (NHS) is likely to be the most comprehensive definition amongst these five other historical definitions; defining oral health as, *"A standard of health of the oral and related tissues that enables an individual to eat, speak, and socialise without active disease, discomfort, or embarrassment, and that contributes to general wellbeing"* (Department of Health: Dental and Ophthalmic Services Division, 2005).

Even though the dynamic meaning of oral health is evident when reviewing the literature, the historical definitions have failed to address this fully. It has been demonstrated that how people perceive oral health changes over the course of a lifetime, and this change is influenced by their medical, cultural and socioeconomic background (Lee *et al.*, 1993; Brondani *et al.*, 2007; Ericsson *et al.*, 2009; Fitzgerald *et al.*, 2015). For example, older people suggested that (with advancement in age) diet played an increasing role in how they perceive their oral health, because of the growing impact it has on their quality of life and enjoyment (Brondani *et al.*, 2007). Patients with dementia considered independent oral care as a prerequisite of optimal oral health-related quality of life, which represent another example of unparalleled way of conceptualising oral health (Ericsson *et al.*, 2009). On the other hand, easy and very low-cost access to dental services was the aspect that shaped what a good oral health meant to people with low-income in New Zealand (Fitzgerald *et al.*, 2015).

Given this deficiency concerning the historical definitions, the World Dental Federation (FDI) proposed a new definition, in order to establish a consensus regarding the concept of oral health (Glick *et al.*, 2016):

> *"Oral health is multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex. Further attributes include that it is a fundamental component of health and physical and mental wellbeing. It exists along a continuum influenced by the values and attitudes of individuals and communities; [it] reflects the physiologic, social, and psychological attributes that are essential to quality of life; [and it] is influenced by the individual's changing experiences, perceptions, expectations and ability to adapt to circumstances."*

The FDI's definition is also not ideal because it states that total absence of disease is a prerequisite for optimum oral health, which may be neither an achievable nor a realistic goal for some people, including dependent adults.

Nevertheless, the FDI's definition was adopted in this PhD project to guide the search process during the literature review and to define the phenomenon of interest in the protocols of the systematic reviews. This is because this definition is one of the most comprehensive ones that may allow establishing a thorough evidence about oral health in dependent adults. In addition, it is the only one that addresses the dynamic nature of oral health, and thus would not contradict the development of a new and unique definition for oral health from the dependent adults' perspective. Lastly, the FDI's definition put more emphasis on the notion that oral health is an integral part of the overall general health and well-being, which may facilitate implementing healthcare practices developed based on it within the non-dental health care professionals.

2.1.2 Measurement of oral health

Early oral health measurement instruments reflected the historical understanding of the concept of oral health, which was predominantly shaped by the biomedical model of health (Coulter *et al.*, 1994). The biomedical model has its roots in the 16th century with the introduction of clinical anatomy as the basis of linking lesions to symptoms (Longino and Murphy, 1995). This model adopted the Newtonian tenet of mechanism, in which nature works according to mechanical laws (Longino and Murphy, 1995). This put more more emphasis on the notion that diseases have places only in body organs and cells (Longino and Murphy, 1995). In addition, this model shared the Descartes concept of dualism that separates the mind from the body (Longino and Murphy, 1995). Furthermore, epistemologically, this model adopted a reductionist approach, which mean that the world can be explained in terms of its constituent parts (Ashcroft and Van Katwyk, 2016). The biomedical model, therefore, represents a paradigm of disease that is purely biological, corresponding to malfunctioning of body mechanisms, and explained in terms of cellular and molecular biology (Ashcroft and Van Katwyk, 2016).

Many early dental researchers and professionals believed that the biomedical model was the most appropriate paradigm for measuring and treating oral and dental diseases (Coulter *et al.*, 1994). Thus, the oral health measurement instruments were largely focused on assessing the objective signs of oral and dental diseases (Coulter *et al.*, 1994). In addition, these instruments adopted a clinician-reported approach and employed quantitative methods of measurement (Coulter *et al.*, 1994). While multiple measurement instruments assessed overall general oral health (e.g. the Oral Health Grading) (Bulman *et al.*, 1968), most of the instruments at that time only assessed a specific aspect of oral health. For example, different measurement instruments were developed to specifically assess dental caries (e.g. the Decayed, Missing, Filled Teeth Index), periodontal diseases (e.g. the Periodontal Disease Index) and malocclusion (e.g. the Handicapping Malocclusion Assessment Record) (Klein and Palmer, 1938; Ramfjord, 1959; Salzmann, 1968). This could reflect the reductive nature of their theoretical bases.

However, this type of measurement instrument has been criticised for a number of potential limitations. First, these instruments only evaluated the oral cavity while ignoring the patients' lived experience, beliefs, emotions, behaviour and social factors of their oral health (Cushing *et al.*, 1986). Thus, these instruments possibly were not able to fully appreciate the burden of oral and dental diseases on the community and individuals (Coulter *et al.*, 1994). In addition, as these instruments adopted a clinician-reported approach, they may have reinforced the paternalistic culture predominant in dental care and treatment at that time (Williams, 2002).

Therefore, a shift started in the 1980s toward developing a new array of oral health measurement instruments based on a more holistic model of illness (i.e. the biopsychosocial model of health), which is also patient-centred (Coulter *et al.*, 1994). Engel (1977) introduced the biopsychosocial model to return medicine to an appreciation of the patient and to understand illness within the full context of the patient's life. Thus, this model takes into consideration the biological, social, psychological and behavioural dimensions of illness (Engel, 1977). Since its development, this model has been utilised in the medical and dental fields to guide research, education and development of new assessments and interventions (MacEntee, 2006).

The oral health measurement instruments (i.e. that were developed based on the biopsychosocial model) were more holistic and comprehensive than the early ones in assessing oral health (Coulter *et al.*, 1994). In addition, most of these instruments adopted a patient-reported approach to understand how the individual perceives the disease and whether they see themselves as ill (Locker, 1988). Adopting the patient-reported approach also allowed for evaluation of whether the disease results in impairment or disability in an individual's life (Locker, 1988). Thus, this type of instruments has been suggested as having a better predictive validity than other instruments for certain outcomes, such as patient initiated dental visits (Coulter *et al.*, 1994). However, while these instruments provide valuable information about oral symptoms and the psychological and functioning problems of the patient, they cannot be used to diagnose oral and dental diseases (Atchison and Dolan, 1990).

Several comprehensive oral health measurement instruments were developed to measure the different dimensions of "oral" health that were introduced by the biopsychosocial model (Locker and Allen, 2007). The Socio-Dental Indicators Index was one of the earliest instruments measuring the social and psychological impacts of oral and dental diseases (Cushing *et al.*, 1986). Another example of this type of instruments is the Geriatric Oral Health Assessment Index, which was developed to assess oral health in older people (Atchison and Dolan, 1990). Lastly, the Oral Health Impact Profile is one of the most widely used instruments that measure a patient's perception of oral diseases' social impact (Slade and Spencer, 1994). Originally, it consisted of a 49-item questionnaire but was modified later to feature a 14-item scale with reportedly similar reliability and validity (Slade, 1997).

2.1.3 Conclusion

For an extended period, the conceptualisation of oral health was predominantly based on the biomedical model of health. This significantly influenced how oral health is defined and measured. However, due to the limitations of the biomedical model, these definitions and measurement instruments have ignored the patients' lived experience of their oral health. In addition, they may contribute to reinforcing the paternalistic culture of providing dental treatment and care. A shift was initiated in the 1980s toward adopting a more holistic and patient-centred paradigm to overcome these limitations. Thus, the biopsychosocial model of health guided the development of a new array of oral health definitions and measurement instruments. These definitions and instruments therefore have considered the biological, social, psychological and behavioural dimensions of oral health. In addition, they may help in the appreciation of the full burden of oral and dental diseases on community and individuals.

Reviewing the literature surrounding the oral health definitions and measurements is crucial because it allows for identification and adoption of an appropriate definition of oral health (i.e. the FDI's definition), which would be used to guide the search process during the literature review and to define the phenomenon of interest in the systematic reviews' protocols. In addition, reviewing the literature about the oral health measurements revealed the complexity of the theoretical bases that underpin the oral health measurement instruments, and thus may offer a starting point to understand how to develop a new oral health measurement instrument.

2.2 Dependency in Adults

2.2.1 Defining dependency and other related concepts

Researchers have suggested that formulating a universal definition of dependency is not easy because this term has been previously employed in various unrelated contexts (Walker, 1982; Gibson, 1995). For example, in the economic field, "dependency" is conceptualised through the lens of the life-cycle theory and it is concerned with populations that are not participating in productive work, and thus are financially supported by others (Walker, 1982; Gardner, 2003). On the other hand, "dependency" in clinical psychology refers to a specific pathological personality trait (Gardner, 2003). People with this trait perceive themselves to be weak and ineffectual, and thus need to attach closely with a significant other for assistance, guidance and approval (Bornstein, 1992; Gardner, 2003). Another meaning of "dependency" exists in the political field, which refers to a reduction in individuals' legal or political rights and their freedom to determine their course of actions (Walker, 1982; Gibson, 1995). Lastly, in social and health care research, "dependency" is usually linked to an individual's need for assistance to undertake activities of daily living (Salvador-Carulla and Gasca, 2010).

Even with these diverse meanings and different uses of the term "dependency", researchers have made enormous efforts to define it and establishing classification schemes for it. Anderson (1971) was amongst the first attempting to universally define dependency, and he stated that dependency is *"a state in which actions by others are a necessary condition for an actor to achieve his or her own goals."* A drawback of this definition is that Anderson did not specify what is "necessary" and by whose criteria. Thus, an alternative definition was proposed by Wilkin (1987) which stated that dependency is *"a state in which an individual is reliant upon other(s) for assistance in meeting recognised need."* Besides defining dependency, many researchers have also created several classification schemes for the concept (Clark, 1972; van den Heuvel, 1976; Walker, 1982; Wilkin, 1987; Fraser and Gordon, 1994; Gibson, 1995). Among these classification schemes, the Gibson (1995) classification appears to be the most comprehensive one (Figure 2.1). It consists of five dimensions: dependency spheres, source of support, dependency needs, dependency causes and dependency attributes (Gibson, 1995). While Gibson (1995) admitted that her classification scheme is neither mutually exclusive nor completely inclusive, it can help in appreciating the full meaning of the concept.

Dependency Spheres	Source of Support	Dependency Needs	Dependency Causes	Dependency Attributes
• Economic • Political/legal • Psychological • Emotional • Mental disability • Physical disability	• Family members • The state • Non-government organisations • Non-family individuals • Employment	• Financial support • Domestic services • Care for self • Care for others • Psychological/ emotional support • Non-violation of civil/legal rights	• Physical impairment • Mental impairment • Not employed • Inadequate income • Legal system • Political system • Psychological/ emotional inadequacy • Caring responsibilities • Life cycle stage • Employment responsibilities	• Legitimacy • Permanency • Naturalness • Necessity • Avoidability • Relational

Figure 2.1: Gibson (1995) dependency classification scheme.

Nonetheless, this PhD project has only focused on a narrow meaning of dependency, known as care dependency, which results from physical or mental disabilities and affects individuals' self-care ability (Boggatz *et al.*, 2007). This choice was made because this form of dependency seems to be the most relevant for oral health and care and have the most significant impact on them. In fact, this form of dependency has been widely used in the health and social care research as a criterion for defining the population of interest (Boggatz *et al.*, 2007).

Like the other forms of dependency, care dependency cannot be considered as a personal attribute of individuals, but as a social relationship that results from a complicated process (Rabiee, 2013). Thus, it is crucial to differentiate between dependent and interdependent relationships. Interdependent relationships are common in modern societies because people at the present time are always depending on each other (Gibson, 1995; Fine and Glendinning, 2005). These interdependent relationships are characterised by mutually beneficial exchanges; while in dependent relationships, the dependent individual usually has nothing to offer (Wilkin, 1987). This could explain why older people (with reduced physical abilities) in non-industrialised societies are not always perceived to be dependents, if they represent the arbiters of disputes and guardians of cultural values in their societies (Wilkin, 1987). Another important characteristic of the dependency relationship is concerned with the power dynamic in which the dependent person usually lacks power in this type of relationship (Strandberg *et al.*, 2003; Fine and Glendinning, 2005; Rabiee, 2013). Thus, older people in care homes who pay for their services, may still consider themselves to be dependent if they do not have control over their life choices (Gibson, 1995; Rabiee, 2013).

Boggatz *et al.* (2007) described the process by which care dependency results from disability through systematically analysing the literature about the care dependency concept. They suggested that care dependency occurs only when an individual's functional ability cannot achieve a recognised need which subsequently results in a perceived self-care deficit (Boggatz *et al.*, 2007). Following this, based on the nature of support required to overcome this deficit, a care dependency relationship can be perceived by a caregiver, care-recipient or both (Boggatz *et al.*, 2007). This conceptualisation of dependency is in line with the learned helplessness theory, which proposes that dependency occurs when individuals notice that their actions do not have a clear consequence on the events in their environment (Peterson, 1993; Peterson *et al.*, 1993).

It must be noted that the previously described relationship between disability (i.e. functional limitation) and perceived dependency is dynamic in nature (Gignac and Cott, 1998). This is because many social forces (e.g. people's personal values, attitudes, cultural norms, societal values and political policies) can play a role in influencing and mediating this relationship (Walker, 1982; Gignac and Cott, 1998; Wang *et al.*, 2004). In other words, these social forces can affect people's subjective perceptions of dependency level regardless of the disability level causing it (Walker, 1982; Gignac and Cott, 1998).

The selective optimisation with compensation model can explain how the disabled individuals' personal values and attitudes may alter their perceived dependency (Baltes and Baltes, 1990). This model explains the adaptation strategies driven by the personal values and attitudes in three interacting elements and processes: selection, optimisation and compensation (Baltes and Baltes, 1990). Selection refers to disabled individuals' decisions to change what they considered as a need, in order to avoid the creation of the self-care deficit state and subsequently dependency on others (Baltes and Baltes, 1990; Baltes, 1995). On the other hand, optimisation describes the disabled individuals' utilisation of new means to maximise the gains from their efforts without being dependent on others (Baltes and Baltes, 1990; Boggatz *et al.*, 2007). Lastly, compensation refers to the individual's acceptance of support in certain tasks without considering themselves to be fully dependent (Baltes and Baltes, 1990). Those individuals usually accept the support to maintain their independence in other key activities or to avoid future pain and further disability (Baltes and Baltes, 1990; Baltes, 1995). The last element of this model is supported by the reports from adults who experienced disability for a long period of time, and who do not consider themselves to be fully dependents if they control the support they receive (Boyle, 2004; Rabiee, 2013).

Another theory that can provide more insight into the dynamic nature of the disability-dependency relationship is known as the learned dependency model, which suggests that dependency occurs when the dependent behaviours of individuals are encouraged and rewarded (Baltes *et al.*, 1980). This can occur particularly in care homes where staff impose and encourage dependency to facilitate providing structured services to all residents (Ellefsen, 2002; Martinsen and Dreyer, 2012; Moe *et al.*, 2013). In addition, imposing dependency can happen as a result of differences in the perceived self-care deficit between the caregiver and the care recipient (Boggatz *et al.*, 2007). Lastly, structural and environmental difficulties can also lead to imposed dependency on individuals (Martinsen and Dreyer, 2012; Rabiee, 2013).

Dependency is a highly relative and subjective social construct, and thus, people usually perceive themselves in a continuum of being more or less dependent within the different areas of their lives (Rabiee, 2013). Nonetheless, Gignac and Cott (1998) proposed a model that can help in classifying individuals in relation to dependency. It classifies adults into four categories, namely, independent, not independent, imposed dependency, and dependent (Gignac and Cott, 1998). A "not independent" individual was defined as one who cannot perform certain tasks and does not receive any assistance either because no assistance is available, or the individual decides not to receive it. On the other hand, "imposed dependency" occurs when an assistant is provided for an individual who is capable of performing the task independently (Gignac and Cott, 1998). In order to be able to fully explore the oral health and its assessment in dependent adults, a pragmatic decision was made to include the following categories "not independent," "imposed dependency," and "dependent" in the population of interest in this PhD project.

As disability represents a key concept in relation to the care dependency, it is briefly described in the following paragraphs. One of the first models created to describe the concept of disability is the Activities of Daily Living (ADL) model (Katz *et al.*, 1959). It was developed after World War II to measure disability and functioning in patients with cancer, as well as in physical rehabilitation (Katz *et al.*, 1959; Salvador-Carulla and Gasca, 2010). It defines disability as the inability to perform certain tasks that considered necessary for daily living (Boggatz *et al.*, 2007). These tasks (according to this model) are divided into "basic" activities such as bathing and dressing; and "instrumental" activities such as light housework and shopping for groceries (Katz *et al.*, 1963; Lawton and Brody, 1969). However, this model has been criticised for viewing disability through a narrow health/disease lens that ignores other personal and environmental factors. Thus, the WHO later developed the International Classification of Functioning, Disability and Health (ICF) model, which aimed to address these factors and adopt a more biopsychosocial/integrative approach (Salvador-Carulla and Gasca, 2010). Currently, the ICF model is one of the most accepted disability models, and it defines disability as, *"an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"* (WHO, 2001; Salvador-Carulla and Gasca, 2010).

Whilst there are a plethora of health conditions that can directly lead to impairments and subsequent disability, the most commonly reported ones are: low back pain, headache disorders, depressive disorders and arthritis/rheumatism (GBD Collaborators, 2018; Theis *et al.*, 2019). Even though disability due to these causes can easily be detected, it might be more challenging to notice disability in a considerable proportion of people, especially older adults, who might develop it gradually and without any obvious cause (Ferrucci *et al.*, 1996; Hardy *et al.*, 2005; Theis *et al.*, 2019). This is because those people usually suffer from one or more risk factors (i.e. frailty and comorbidity) that can increase their risk of developing a disability (Fried *et al.*, 2004; Kuzuya, 2012). In fact, disability in those people has been found to be a complex and a highly dynamic process, in which they continually fluctuate between the statuses of disability and functionality (Verbrugge *et al.*, 1994; Hardy *et al.*, 2005; Gill, 2014). Thus, it is necessary to understand these risk factors that can influence this fluctuation and increase the risk of developing disability (Fried *et al.*, 2004; Kuzuya, 2012).

Several studies found that frailty increases the number and duration of disability episodes in an older population (Hardy *et al.*, 2005; Gill, 2014). Although there is no consensus among geriatricians regarding the definition of frailty, most of them believe that it is different from disability and is a clinical syndrome that increases vulnerability to stressors and leads to deterioration in physical performance and to adverse health outcomes (Sternberg *et al.*, 2011; Rodriguez-Manas *et al.*, 2013; Chen *et al.*, 2014). One of the most comprehensive definitions of frailty was proposed by Kuzuya (2012) that frailty is, *"geriatric syndrome of decreased reserve and resistance to stressors, resulting from cumulative declines across multiple physiologic systems, and leading to adverse health outcomes including physical disability, falls, hospitalization, institutionalization and mortality."*

Numerous operational definitions of frailty have been suggested that identify frail elderly according to phenotypic criteria (Sternberg *et al.*, 2011; Chen *et al.*, 2014). The most widely used phenotypic operational definition was that suggested by Fried *et al.* (2001), which identifies a person as frail if at least three out of five manifestations are present: weight loss, reduced grip strength, exhaustion, reduced walking time and reduced physical activity. Another unique concept for measuring frailty was developed by Mitnitski *et al.* (2001), which evaluates the degree of frailty based on the proportion of accumulated deficits, such as symptoms, signs, functional impairments, and laboratory abnormalities. While most of the previous definitions focused only on the physical aspect of frailty, recently an increased number of researchers recommend including cognition as a component of the frailty definition (Rothman *et al.*, 2008; Avila-Funes *et al.*, 2009; Kelaiditi *et al.*, 2013).

Comorbidity or multimorbidity is an easy concept to comprehend. Comorbidity is the coexistence of two or more chronic and non-communicable diseases that synergistically cause adverse health outcomes (Fried *et al.*, 2004). It was found to increase the risk of developing frailty and disability (Fried *et al.*, 2004; Villacampa-Fernandez *et al.*, 2017). Comorbidity was defined by Le Reste *et al.* (2015) as, *"any combination of chronic disease with at least one other disease (acute or chronic) or biopsychosocial factor (associated or not) or somatic risk factor. Any biopsychosocial factor, any risk factor, the social network, the burden of diseases, the health care consumption, and the patient's coping strategies may function as modifiers (of the effects of comorbidity)."*

Dependency after stroke as a representative model of care dependency in adults

While this PhD project has focused on a narrow sphere of dependency (care dependency), this form of dependency still encompasses a highly diverse population. This diversity is demonstrated by the infinite number of causes that can lead to disability and subsequent dependency on care (GBD Collaborators, 2018; Theis *et al.*, 2019). In addition, based on the cause of disability, dependency on care can have different prognoses and outcomes (Syrjala *et al.*, 2004; Hopkins and Jackson, 2006; Ullberg *et al.*, 2015). Furthermore, dependency on care, due to a certain level of disability, is not perceived similarly by different people because of many social forces (Gignac and Cott, 1998; Wang *et al.*, 2004). Thus, in primary research studying dependent adults, it might be challenging from a feasibility point of view to generate a sample that adequately represents the diversity of the whole population. It is arguably more efficient to select a subset from the dependent adult population that can sufficiently reflect the variability within the entire population, and thus can help in understanding the research topic in relation to the whole population.

For the primary qualitative study (in Chapter 6), patients with a care dependency after a stroke have been selected as a representative model of the adults who are dependent on care. Stroke is a serious cerebrovascular disease that occurs when a restricted blood flow to a part of the brain leads to the sudden death of brain cells in that region (Sacco *et al.*, 2013). Haemorrhage in the brain that leads to an increase in intracranial pressure could also cause a stroke (Sacco *et al.*, 2013). Stroke is one of the major causes of adult disability and dependency (Lozano *et al.*, 2012). It is estimated that among the 50 million stroke survivors worldwide, 25 % to 74 % of them have some form of disability, and thus they are being partially or completely dependent on others to undertake ADL (Carmo *et al.*, 2015).

Several risk factors of stroke have been identified. Stroke incidence is greater in men than women, and the risk increases as they are getting older (Roger *et al.*, 2012; Boehme *et al.*, 2017). The genotype of patients has been identified as a potential risk factor (Schulz *et al.*, 2004). Many systemic diseases also were reported as risk factors such as diabetes mellitus, heart disease, and high blood pressure (Lewington *et al.*, 2002; Banerjee *et al.*, 2012; Yiin *et al.*, 2014). Several lifestyle habits including smoking, alcohol consumption, and insufficient physical activity were also associated with a higher risk of stroke (Klatsky *et al.*, 2001; Bhat *et al.*, 2008; Boehme *et al.*, 2017).

Dependency on care after stroke can vary substantially between patients. By selecting this patient group for investigation in this PhD, it was intended the project would reflect diversity among the entire population of dependent adults. The variability of dependency after stroke can be manifested in three main areas. First, disability after stroke can occur due to physical causes, mental causes or both. One of the main physical-related causes of disability after stroke is the muscular paralysis that occurs in the contralesional side of the body (Carvalho-Pinto and Faria, 2016). Paralysis after stroke can result in weakness or loss of muscular control, which adversely affect the ability to undertake ADL (Harris and Eng, 2007; Carvalho-Pinto and Faria, 2016). This can be compounded by sensory disturbances, which are deteriorations in the sensory perception occurring on the paralysed side of the body (Martino *et al.*, 2005). Mental-related causes of disability after stroke could affect patients' memory, learning, and awareness, and thus their ability to independently undertake the ADL. An example of these causes is the hemispatial neglect condition, which is a syndrome of a perceptual attention problem that prevents patients from recognising and acknowledging stimuli from the contra-side of the brain lesion (Parton *et al.*, 2004). Another example of mental-related causes of disability is anosognosia which refers to the patients' inability to acknowledge the reality of the physical impairments resulting from stroke (Jehkonen *et al.*, 2006).

Another demonstration of the variability of the care dependency after stroke is in the differences in its trajectories (prognoses) among the stroke survivors. While many studies have reported that the prevalence of disability after stroke remains relatively stable up to 10 years (Wolfe *et al.*, 2011; Luengo-Fernandez *et al.*, 2013), these reports may not truly reflect the dynamicity at the individual level. Rejnö *et al.* (2019) investigated the trajectories of disability after stroke by stratifying their sample according to the patients' ADL status, and they found that during the five-year study period, stroke survivors continually fluctuated between the state of dependency and independency. They attributed the stability of ADL dependency prevalence after stroke to the balance between the death of ADL-dependent individual and a net flow of survivors converting from independency to dependency (Rejnö *et al.*, 2019).

Lastly, the sociodemographic of the dependent patients after stroke might vary widely. Dependent patients after a stroke may live in a wide variety of settings, including hospitals, care homes and their community (Lee *et al.*, 2011). It has been found that up to 20 % of stroke survivors live in care homes, which represent an increase by around 50 % before stroke (Hardie *et al.*, 2004; Appelros *et al.*, 2006). In addition, although stroke patients tend to be older, they can also be relatively young (Lee *et al.*, 2011). In fact, several recent studies noted an increase in the incidence of stroke among younger groups, which was attributed to the improvement in the sensitivity of diagnostic testing (Feigin *et al.*, 2014; Boehme *et al.*, 2017).

2.2.2 Measurement of care dependency

Even though it was clear from the previous section that disability does not necessarily equate to care dependency, all the instruments identified during this literature review have measured care dependency by assessing functional ability as a surrogate measure of dependency (Norburn *et al.*, 1995; Sikkes *et al.*, 2009; Hopman-Rock *et al.*, 2019). These measurement instruments assessed care dependency in terms of the need for assistance in basic ADL, instrumental ADL, or both (Mlinac and Feng, 2016). However, the inconsistency among these instruments regarding which components of the ADL to be measured (i.e. basic or instrumental) can explain the enormous variation in the reported prevalence of care dependency by different studies (Stone, 2003; Salvador-Carulla and Gasca, 2010). In addition, as these instruments have ignored the social aspect of the care dependency (Gibson, 1995; Salvador-Carulla and Gasca, 2010; Fong *et al.*, 2015), the data obtained using them may not reflect the true reality. Another criticism of these instruments is that each of them has been developed for a specific population of dependent adults, and thus it might be difficult using them to estimate the prevalence and trend of care dependency in the general population (Wilkin, 1987). Lastly, several systematic reviews evaluating these instruments' psychometric (measurement) properties have suggested that more studies are still needed to establish a strong evidence base of their psychometric performance (Sikkes *et al.*, 2009; Hopman-Rock *et al.*, 2019).

The ADL measurement instruments can be classified according to their method of input into two main categories: questionnaire-based and performance-based measurement instruments (Mlinac and Feng, 2016). The questionnaire-based measurement instruments can be completed by the dependent adults or their caregivers. Caregivers are usually consulted when the dependent adults cannot provide insight into their functional impairments (Desai *et al.*, 2004; Jekel *et al.*, 2015). Although the instruments utilising caregivers' input are usually completed by those who know the dependent adults well, the caregivers still can be biased by the burden of care they provide (Mlinac and Feng, 2016). Thus, the findings of this type of instruments may over or underestimate the true dependent adults' functional ability (Cotter *et al.*, 2002). On the other hand, while the instruments utilising dependent adults' input are arguably more convenient and accurate, they have limited application when used with dependent adults experiencing a decline in their cognitive ability (Miller *et al.*, 2013; Jekel *et al.*, 2015; Mlinac and Feng, 2016).

The other category of the ADL measurement instruments concerns those undertaken by observing the dependent adults while performing the ADL activities (Mlinac and Feng, 2016). Although these instruments are more objective than the questionnaire-based instruments, they generally require more training to administer (Mlinac and Feng, 2016). Another limitation concerning the performance-based instruments is that it is difficult to know the reason behind the dependent adults' failure in performing the tasks. This is because the failure may reflect the dependent adults' refusal rather than their functional disability (Mlinac and Feng, 2016). Thus, it has been suggested that the best approach to evaluate the care dependency is by utilising a combination of both a performance-based instrument and a questionnaire-based instrument that is completed by dependent adults (Bravell *et al.*, 2011).

2.2.3 Prevalence and trend of care dependency

Many epidemiological studies have calculated the prevalence and trends of care dependency, as well as forecasting its future. However, as explained previously, the instruments used in these studies are not ideal for measuring care dependency, and thus the accuracy of their findings might be difficult to ascertain. Most of these studies indicate that the prevalence and incidence of disability and subsequent dependency on care has increased globally over time (GBD Collaborators, 2018; Theis *et al.*, 2019). For example, the years lived with disability have globally increased from 562 million years in 1990 to 853 million years in 2017 (GBD Collaborators, 2018). This increase was reported despite a decrease in the incidence of many health conditions such as stroke and dementia that are major causes of disability (Koton *et al.*, 2014; Matthews *et al.*, 2016). The increase in the care dependency prevalence was attributed to the worldwide increase in life expectancy in the last century, which led to a significant increase in the number of older people who are frail and comorbid and thus at higher risk of being dependent on care (Salisbury *et al.*, 2011). In addition, the care dependency increase was attributed to the worldwide rise in obesity and overweight, which is a risk factor for many health conditions leading to disability (Stevens *et al.*, 2012; Kingston *et al.*, 2018).

Because a substantial proportion of the dependent adult population is older people, and their proportion is expected to increase even more in the future, most forecasting studies focused on estimating the care dependency among them (Chen *et al.*, 2016; Kingston *et al.*, 2018). For example, although it is expected that the proportion of independent older people between 2015 and 2035 will increase in England, the absolute number of dependent older adults is expected to also increase by approximately one-third (Kingston *et al.*, 2018). The increase in the proportion of independent older adults is expected to be due to the reduction in the rate of dependency among the youngest group (65–74 years) (Kingston *et al.*, 2018). However, the increase in the absolute number of the dependency cases was suggested to be due to the increase in the number of older people reaching 85 years with a higher risk of developing care dependency (Kingston *et al.*, 2018). Chen *et al.* (2016) reported comparable findings from forecasting the prevalence and trend of care dependency in Japan.

2.2.4 Consequences of care dependency

Dependency could negatively impact three main life aspects of the adults with functional limitations: quality of care, well-being and economic. First, dependent adults may not receive optimal support and assistance in the self-care domain (Piredda *et al.*, 2015). One of the reasons explaining the suboptimal care provided for dependent adults is the lack of balance in the power dynamic between the dependent adults and their caregivers (Strandberg *et al.*, 2003; Fine and Glendinning, 2005; Rabiee, 2013). This is demonstrated by numerous observations suggesting that many dependent adults do not have the courage to criticise the quality of unsatisfactory care provided by their caregivers (Strandberg *et al.*, 2002; Strandberg *et al.*, 2003). In fact, many dependent adults expressed their lack of confidence about asking for help from their caregivers (Strandberg *et al.*, 2003). This is because they believe criticising or asking for unreasonable help may overburden their caregiver, and thus increase the risk for being punished by not receiving the care they need (Strandberg *et al.*, 2003). Thus, many dependent adults have described how they learned to ask for help in a “proper way” (Strandberg *et al.*, 2000; Strandberg *et al.*, 2003). This includes being nice, kind and sociable to demonstrate that they are easy individuals to work with, as well as keeping their requests to a minimum (Strandberg *et al.*, 2003; Piredda *et al.*, 2015).

Dependent adults’ refusal to receive care is another factor explaining the less than optimal care provided for them. This is because many dependent adults change what they perceive as needs, in order to reduce dependency on others, which then allows them to present themselves as strong individuals (Baltes and Baltes, 1990; Baltes, 1995; Strandberg and Jansson, 2003). This refusal can also stem from their desire to avoid any stigma felt to be associated with being disabled or dependent (Rabiee, 2013).

Lastly, many environmental-related factors can act as a barrier that prevents providing optimal care for dependent adults (Robbins *et al.*, 2013). These environmental factors have been acknowledged by the dependent adults and their caregivers, and they are usually relevant to the care home setting (Strandberg *et al.*, 2003; Robbins *et al.*, 2013). One of the main environmental barriers is the lack of sufficient financial funds (Kupeli *et al.*, 2018). This may explain why many care homes are ill-equipped to provide optimal care (Kupeli *et al.*, 2018). In addition, these financial constraints can also result in a relatively high staff turnover and low total staff number due to the limited professional development opportunities, low pay and low job satisfaction (Park *et al.*, 2015; Kupeli *et al.*, 2018). Another environmental factor is the lack of adequate training and education support, which hamper the ability of care home staff to deliver high-quality care (Kupeli *et al.*, 2018). Lastly, the lack of clear institutional policies and protocols about providing care for dependent adults can adversely affect the quality of care (Park *et al.*, 2015).

The suboptimal care provided to dependent adults is one of the factors that can explain the association between being dependent and the deterioration of the well-being and quality of life (Piredda *et al.*, 2015). From the dependent adults' perspective, suboptimal care could have several meanings. It could simply mean that the provided care is not satisfying their needs (Piredda *et al.*, 2015). However, it could also mean that the care is provided in a way that lacked respect, empathy and personal touch (Ellefsen, 2002; Strandberg *et al.*, 2003; Moe *et al.*, 2013). Deterioration in the dependent adults' well-being due to the suboptimal care is usually manifested as feelings of powerlessness, insignificance, frustration and desperation (Ellefsen, 2002; Strandberg *et al.*, 2003; Moe *et al.*, 2013).

Another explanation for the decline in the dependent adults' well-being is attributed to changes in their perceived self-image (Strandberg and Jansson, 2003; Piredda *et al.*, 2015). Changes in the self-image of dependent adults occur because being dependent on others create a new reality for the dependent adults that alters how they may perceive themselves (Strandberg and Jansson, 2003; Piredda *et al.*, 2015). In their meta-synthesis about the impact of care dependency on adults, Piredda *et al.* (2015) attributed the changes in the self-image to the effect of dependency on revealing or obscuring the dependent adults' body or personality. Dependency can reveal the functional limitations of the dependent adults to themselves and others (Hammarström and Torres, 2010; Lykkegaard and Delmar, 2013). On the contrary, by revealing these functional limitations, the personhoods of the dependent adults might be obscured as the adults are only recognised through their dependency, which overshadows all other aspects of their identity (Schröder-Butterfill and Fithry, 2014; Piredda *et al.*, 2015). These changes in self-image are not easily accepted or tolerated by dependent adults, and have been found to lead to feelings of shame, powerlessness and frustration (Gignac *et al.*, 2000; Hammarström and Torres, 2010; Lykkegaard and Delmar, 2013).

Lastly, a reduction in social value due to dependency could adversely affect the well-being of dependent adults. In modern societies, the value of people mostly stems from their productivity and autonomy (Strandberg *et al.*, 2003; Schröder-Butterfill and Fithry, 2014). The acquisition of these two competencies represents the successful transition from childhood to adulthood (Schröder-Butterfill and Fithry, 2014). Thus, these competencies form the foundation of the conceptions of individual personhood in modern societies (Piredda *et al.*, 2015). However, dependency can undermine both of these competencies, and thus potentially reduce the social value of the dependent adults (Strandberg and Jansson, 2003; Strandberg *et al.*, 2003). The reduction in social value could adversely affect dependent adults by socially marginalising them and spatially separating them from society (Lawton, 1998). In addition, the deterioration in the social value of dependent adults can again create feelings of imprisonment, powerlessness, and frustration (Strandberg *et al.*, 2003). It has been reported that some of the adults with functional limitations might reject assistance and support to fulfil their needs, in order to protect their social value (Strandberg and Jansson, 2003).

The negative effect of care dependency on the adults' well-being is supported by several cross-sectional studies that evaluated the association between dependency in adults and their quality of life (González-Salvador *et al.*, 2000; Dijkstra *et al.*, 2015). However, other studies did not demonstrate such an association (Tabali *et al.*, 2013; Tabali *et al.*, 2015), which might be attributed to their comparatively smaller sample sizes. In addition, these latter studies evaluated the health-related quality of life, which may not overlap quality of life domains that are affected by care dependency (Tabali *et al.*, 2013; Tabali *et al.*, 2015).

However, it must be noted that care dependency does not always have a negative impact on the well-being of dependent adults (Piredda *et al.*, 2015). This is because some dependent adults appreciate that being dependents helps them meeting needs that would be unmet without the assistance and support from others (Larsson *et al.*, 2009; Larsson *et al.*, 2010). In fact, it has been reported that adults with functional limitations might view dependency as a liberating factor that allowed them to live their desired life (Martinsen and Dreyer, 2012; Piredda *et al.*, 2015). Thus, many dependent adults are grateful to and admire their caregivers (Strandberg *et al.*, 2003). In addition, the state of dependency can highlight to the dependent adults the other abilities they still can master, which can be a new source of joy for them (Strandberg *et al.*, 2003). Lastly, dependency can provide an opportunity for adults with functional limitations to establish relationships with loving, altruistic and helpful people (Piredda *et al.*, 2015).

The last aspect of the dependent adults' lives affected by their dependency is their economic status. While researchers have traditionally focused on exploring how poverty could lead to disability and subsequent dependency, recent studies demonstrated that dependency can result in a decline in the economic status of dependent adults and their families (Dushi and Rupp, 2013; Guerchet *et al.*, 2018). These studies evaluated the economic status of adults after being dependent based on three main criteria: household income, cost of living and household assets.

Dependency has been proposed to negatively impact the economic status of the dependent adults and their families due to its detrimental effect on household income (Guerchet *et al.*, 2018). The reduction in household income can be attributed to the deteriorated capability of dependent adults to undertake productive work (Guerchet *et al.*, 2018). In addition, several family members have been found to need to cut back on paid work to take care of their dependent relatives (Guerchet *et al.*, 2018). In a longitudinal study in the United States of America (USA), it has been found that disability associated with a 53 % reduction in the median income among people with disabilities, where public and private benefits only replacing less than half of their losses (Dushi and Rupp, 2013). In addition, the reduction in the income among people with disabilities in the USA is supported by the Medicare recipient data indicating that disabled people are twice as likely to be eligible for low-income subsidies in comparison to the independent cohort (Tajeu *et al.*, 2013). Similar findings of the reduction in the household income of dependent adults have also been reported from other developed and developing countries (Schofield *et al.*, 2013; Guerchet *et al.*, 2018).

An increase in the costs of living, including paid health or formal care, is another reason for prevalent poverty among dependent adults' families (Guerchet *et al.*, 2018). Economists have estimated the costs of disability at the household level (Guerchet *et al.*, 2018). The extra cost of disability in the United Kingdom (UK) has been estimated to be 20–50% of the household income (Zaidi and Burchardt, 2005). In Ireland, this cost has been found to account for up to one-third of household income (Cullinan *et al.*, 2013). Factors such as disability severity and the size of the households play a role in determining the cost of living with a disability (Cullinan *et al.*, 2013). However, when the cost of disability has been estimated based on the household expenditure, no extra cost was detected, which might be because families had to cut on their expenses due to the reduction in household income (Guerchet *et al.*, 2018).

Lastly, it has been found in many cross-sectional studies that dependent adults' families usually have significantly fewer household assets compared to families with no dependent adults (Guerra *et al.*, 2008; Teerawichitchainan and Knodel, 2015). However, these findings must be interpreted carefully as longitudinal studies failed to identify such association (Guerchet *et al.*, 2018). Thus, it is possible that the members of families with fewer household assets are at higher risk for developing dependency from the beginning.

2.2.5 Conclusion

Dependency on care is a social construct that does not represent a personal attribute of individuals, but a social relationship between them. There are two key characteristics of any care dependency relationship: a dependent adult lacking power in the relationship especially in making decisions; and a lack of the capacity to pay back. Care dependency can promptly occur because of physical- or mental-related conditions causing disability. However, care dependency can develop gradually in older adults due to frailty or comorbidity. Even though care dependency is a highly dynamic, relative and subjective social construct, an operational definition was adopted to facilitate defining the population of interest in this PhD project. A dependent adult within the context of this thesis was defined as an eighteen-year-old or older individual who needs or receives assistance due to a reduction in mental capacity or physical capability. In addition, as dependency on care encompasses a highly diverse population, patients after stroke were selected as a representative model of care dependency in adults to be utilised in the primary study.

Even with the limitations of the instruments measuring care dependency, it is clear that dependency in adults represents an emerging phenomenon. This trend is demonstrated by the increase in the prevalence of dependency among adults in recent decades, as well as the expected future growth. Thus, more research might be needed to further our understanding of many aspects that still are not well understood about dependent adults. Oral health and care are possibly an example of these aspects that need more investigation due to their relevance to the dependent adults. The relevance of oral health and care to dependent adults could be inferred from the general impact of dependency on adults. For example, one of the dependency consequences is the deterioration in the self-care domain, which include oral care. In addition, dependency undermines the well-being of dependent adults, which could adversely affect their attitude toward oral health and care. Lastly, dependency can cause a decline in the economic status of the dependent adults and their families, which may limit their access to optimal dental services.

2.3 Oral Health in Dependent Adults

2.3.1 Oral health status of dependent adults

A number of studies have explored and investigated the status of oral health in dependent adults. The results generally indicate that most aspects of oral health are possibly in a suboptimal condition. Oral hygiene is one of the main aspects that have been shown to be poor in dependent adults, and this can be manifested as an increase in dental plaque and calculus build-up or as an increase in halitosis prevalence (Pakpour *et al.*, 2016; Karolyhazy *et al.*, 2018; Yoon *et al.*, 2018). Yoon *et al.* (2018) estimated that approximately one-third of the dependent residents in Canadian care homes have bad breath. In addition, more than one-quarter of dependent adults due to dementia were estimated to experience an abundant amount of dental plaque accumulation (Delwel *et al.*, 2019). Several cross-sectional studies have shown a clear association between the level of disability and the amount of dental plaque accumulation (Petrovic *et al.*, 2016; Delwel *et al.*, 2019). Other studies, utilising a retrospective cohort design, have demonstrated a statistically significant higher level of dental plaque and calculus build-up among the dependent adult groups (including stroke survivors and patients with spinal cord injury) (Pakpour *et al.*, 2016; Karolyhazy *et al.*, 2018). However, a retrospective cohort study investigating oral health in Parkinson's disease patients could not demonstrate any significant difference in the dental plaque scores between the patients and their healthy controls (Ribeiro *et al.*, 2016). The statistically insignificant outcomes in this study might be attributed to its considerably smaller sample size (i.e. only 17 patients were recruited).

Dependent adults have been reported to experience a high level of dental decay (Delwel *et al.*, 2017). Studies evaluating the dependent adults' dental health have often utilised the Decayed Missing Filled Teeth (DMFT) Index as the caries outcome measure (Ribeiro *et al.*, 2016; Delwel *et al.*, 2017; Karolyhazy *et al.*, 2018). However, many of these studies could not demonstrate any significant difference between the dependent adults and the matching independent ones (Ribeiro *et al.*, 2016; Karolyhazy *et al.*, 2018). This can be attributed to one major drawback of the DMFT Index; as it gives an equal weight to the decayed, missing, and filled teeth when calculating the total score (Broadbent and Thomson, 2005). This drawback can be overcome by using a more sensitive index such as the International Caries Detection and Assessment System (ICDAS), which is more sensitive in evaluating different stages of the caries process (Ismail *et al.*, 2007).

Nonetheless, analysing the different components of the DMFT Index separately might provide a more accurate picture of the dependent adults' dental health than analysing the total score.

Dependent adults, regardless of what caused the dependency, tend to have up to four-times more missing and decayed teeth than independent individuals (Dordevic *et al.*, 2016; Delwel *et al.*, 2017; Aragon *et al.*, 2018; Karolyhazy *et al.*, 2018). This high level of dental problems is also supported by cross-sectional studies, which have demonstrated a significant correlation between the level of disability the number of teeth missing or decayed (Petrovic *et al.*, 2016; Saintrain *et al.*, 2018; Delwel *et al.*, 2019). It must be noted that the high prevalence of missing teeth in dependent adults may not necessarily reflect their true caries experience, because teeth can be lost for many reasons other than dental caries (Broadbent and Thomson, 2005).

The high prevalence of missing teeth among dependent adults is reflected on their higher utilisation of removable partial dentures when compared to independent adults (Aragon *et al.*, 2018; Karolyhazy *et al.*, 2018). However, the quality of these dentures was not always found to be optimal. For example, these dentures could have problems with occlusion, retention and fitting (Foley *et al.*, 2017; Delwel *et al.*, 2018b). In addition, they have been reported to increase the risk of denture stomatitis (Yoon *et al.*, 2018). Thus, dentures can be a source of discomfort and pain for dependent adults (Yoon *et al.*, 2018).

In contrast to the missing and decayed teeth statistics, dependent adults usually have less filled teeth than independent individuals (Dordevic *et al.*, 2016; Aragon *et al.*, 2018; Karolyhazy *et al.*, 2018). This was attributed to the nature of dental treatment provided for them, which focuses more on extraction rather than restoration (Karolyhazy *et al.*, 2018). Only one study has reported that dependent patients, due to spinal cord injury, have more restored teeth than the healthy matching participants (Pakpour *et al.*, 2016). The authors of this study attributed this finding to the greater availability and accessibility to dental care in Iran (i.e. where the study was conducted) for those patients (Pakpour *et al.*, 2016).

Choi *et al.* (2017) used a novel approach to assess caries activity in dependent adults due to age-related causes. They assessed the caries activity by evaluating the acidogenicity of sampled dental biofilms (Choi *et al.*, 2017). They found that the acidity of the dependent adults' dental biofilms was 10% higher than independent individuals (Choi *et al.*, 2017). Even though the difference was statistically significant between the two groups, they did not explain how this difference can be clinically significant.

Periodontal health is another aspect of oral health that can deteriorate as a result of the poor oral hygiene in dependent adults. In fact, periodontal diseases have been found to be highly prevalent among dependent adults (Petrovic *et al.*, 2016; Aragon *et al.*, 2018; Karolyhazy *et al.*, 2018). It has been estimated that four out of five dependent adults, due to age-related causes, have moderate to severe gingival inflammation (Yoon *et al.*, 2018). In addition, a significant correlation was identified between the level of mental disability and the severity of gingival inflammation when measured with the Löe and Silness Gingival Index (Petrovic *et al.*, 2016). The high prevalence of gingival inflammation explains why dependent adults experience 2.5 times more gingival bleeding than independent individuals (Choi *et al.*, 2017; Karolyhazy *et al.*, 2018). In addition, dependent adults have been reported to experience more periodontitis than independent people (Pakpour *et al.*, 2016; Karolyhazy *et al.*, 2018). For example, the clinical attachment loss in stroke survivors, who are dependent on care, was found to be double that of the healthy participants (Karolyhazy *et al.*, 2018). Many studies also found that periodontal pockets to be a widespread finding in the dependent adult populations (Pakpour *et al.*, 2016; Karolyhazy *et al.*, 2018; Delwel *et al.*, 2019). Lastly, dependent adults have been reported to be diagnosed with other mucosal lesions such as cheilitis, candidiasis and mouth dryness (Aragon *et al.*, 2018; Yoon *et al.*, 2018).

In light of the previously described oral health problems, it is perhaps not surprising that dependent adults are at high risk of experiencing orofacial pain. However, the topic of orofacial pain in dependent adults has received little research attention (Delwel *et al.*, 2017). The study reported by de Souza Rolim *et al.* (2014) found that one of every five dependent Alzheimer's patients (i.e. at one point in time) suffer from orofacial pain, and this proportion was three-times higher than that of the control group. Another investigation utilising more comprehensive examination revealed that this proportion can be even higher among the dependent Alzheimer's patients (i.e. one of every four patients) (Delwel *et al.*, 2019). However, because both studies have only used self-reported orofacial pain measurement instruments, due to the absence of a valid and reliable clinician-reported orofacial pain instrument, there is still limited information about the orofacial pain in dependent adults who cannot verbalise (Delwel *et al.*, 2019).

There have been a number of methodological limitations in the studies assessing oral health in dependent adults, which may limit outcome accuracy. First, most of these studies were mislabelled as “case-control” studies, while in fact they have utilised a retrospective cohort design. This is because patients and controls in these studies were identified based on the risk factor (being dependent/independent), and not by the outcome (oral health status). The retrospective cohort studies cannot provide robust evidence about the causality, and therefore determining the direction of the relationship between the dependency and oral health decline is not possible. In addition, most of these studies did not consider all of the possible confounding factors. For example, Karolyhazy *et al.* (2018) did not consider the socioeconomic level of their participants, which resulted in a statistically significant difference between stroke patients and controls. Thus, the greater oral health decline in the stroke patients might be attributed to the lower socioeconomic level and not to the dependency. Another example of this kind of limitation is in the study by Aragon *et al.* (2018), who did not consider the age of the participants. Lastly, many of the outcome measures that have been used in these studies (e.g. the DMFT Index and the clinical attachment loss) evaluate the historical condition of oral health. Thus, the oral health decline recorded by these instruments may not only reflect oral health deterioration occurring after dependency.

2.3.2 Causes of oral health decline

Many factors are responsible for the oral health decline in dependent adults. These factors can be classified into the following: barriers to oral care and barriers to dental treatment.

Barriers to oral care

Some barriers to oral care are related to the dependent adults themselves. One of the most frequently mentioned barriers to providing adequate oral care to dependent adults is their refusal to accept it. Eighty percent of the care homes’ staff believed that dependent adults' refusal is a major barrier for providing oral care (Wårdh *et al.*, 2012). In addition, nurses in hospitals estimated that half of their dependent patients would refuse assistance with oral care (Coker *et al.*, 2017a). This refusal has been attributed to dependent adults’ desire to maintain their independence (Gopalakrishnan *et al.*, 2019), which is in line with the wider literature exploring their reactions to dependency upon care (Rabiee, 2013). However, this refusal may be a result of dependent adults overestimating their ability to undertake independent oral care (De Visschere *et al.*, 2015).

Dependent adults' misunderstandings about oral health and care, as well as their previous oral hygiene practices could be another reason for their refusal to receive assistance and support in oral care. Dependent adults may not appreciate the importance of oral health and care at the current stage of their life, nor understand the negative consequences of oral health deterioration (Wårdh *et al.*, 2012; De Visschere *et al.*, 2015; Horne *et al.*, 2015; Coker *et al.*, 2017a). These misunderstandings about oral health and care may adversely affect dependent adults by leading them to be resigned to their poor oral health, and thus not seeking oral care or refusing it (De Visschere *et al.*, 2015). However, for other dependent adults, oral health and hygiene may never have represented an important aspect in their life, and therefore the refusal of oral care is only representing an extension of their long-standing beliefs and habits (Wårdh *et al.*, 2000).

Even though dependent adults, regardless of the dependency cause, can refuse receiving oral care, their refusal in most studies was usually linked to the dependent patients suffering dementia. This group of patients have been reported to exhibit uncooperative behaviours toward oral care (Hearn and Slack-Smith, 2016). These uncooperative behaviours have been reported to manifest as verbal and physical violence, refusal to open their mouths or taking dentures out (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015). It has also been suggested that patients with dementia may not have the cognitive capacity to understand or follow the caregiver's oral care instructions (Wårdh *et al.*, 2000; Horne *et al.*, 2015; Gopalakrishnan *et al.*, 2019).

While several non-pharmacologic and relationship-based interventions have been developed to manage dependent adults' refusal, these were found to be not always effective (Jablonski *et al.*, 2011; Zimmerman *et al.*, 2014; Hoben *et al.*, 2017; Jablonski *et al.*, 2018). This can put caregivers in an ethical dilemma. Accepting the refusal from the dependent adults could adversely affect their oral and general health (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015). On the other hand, forcing oral care onto individuals could impinge on their dignity and self-esteem (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015). Thus, many caregivers believe that ethical consultation with the physician and family is required when dependent adults with a reduction in their cognitive capacity refused oral care (De Visschere *et al.*, 2015).

The last barrier related to dependent adults for providing oral care is the increase in the proportion of dependent adults who are not edentulous (Dharamsi *et al.*, 2009; Hearn and Slack-Smith, 2016). This barrier is particularly relevant to dependent adults due to age-related causes because more people currently are surviving into old age with more natural teeth (Information Centre for Health and Social Care: Office for National Statistics, 2012). Providing oral care for dependent adults with natural teeth has been suggested to be more challenging than providing it for edentulous adults with dentures (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015; Hearn and Slack-Smith, 2016). This is because tongue could obstruct the oral care when brushing the teeth, which is not the case when cleaning dentures outside of the mouth (De Visschere *et al.*, 2015). In addition, brushing dependent adults' teeth may induce gagging and vomiting (De Visschere *et al.*, 2015). Furthermore, many dependent adults may face difficulty with keeping their mouth open, rinsing or swallowing (De Visschere *et al.*, 2015). These difficulties can have the greatest impact on dependent adults with heavily restored dentition and advanced restorative work (Smith and Thomson, 2017).

There are many other factors that are related to the caregivers of dependent adults and could prevent the provision of optimal oral care. Many of these factors have been suggested to originate from the caregivers' lack of knowledge and skill about oral health and care. The lack of knowledge and skill can adversely affect the quality of oral care provided by the caregivers, as well as their confidence in providing such care (Yeung and Chui, 2010; Horne *et al.*, 2015; Smith and Thomson, 2017). One of the major problems associated with lack of knowledge and skill is the caregivers' inability to recognise oral health problems in dependent adults (Wårdh *et al.*, 2000; Smith and Thomson, 2017). In addition, the lack of knowledge and skill can compromise the caregivers' ability to provide oral care for dependent adults with challenging behaviours such as dementia patients (Smith and Thomson, 2017). In fact, several studies have reported that some caregivers may lack the skill and knowledge to provide optimal regular oral care (e.g. tooth brushing and dental flossing) for even the most cooperative dependent adults (Dharamsi *et al.*, 2009; Wårdh *et al.*, 2012; De Visschere *et al.*, 2015).

The lack of knowledge about the significance of oral health and care could also play a role in reducing their perceived importance by caregivers, which can create another barrier for providing adequate and continuous oral care for dependent adults (Wårdh *et al.*, 2012; Coker *et al.*, 2017a). For example, many care home staff believe that losing teeth is an inevitable consequence of ageing regardless of the nature of oral care provided (Wårdh *et al.*, 2012). In addition, some intensive care unit nurses believe that the decline in oral health has only a minimal impact on the dependent patients' general health (Yeung and Chui, 2010). Such beliefs resulted in oral health and care not always to be a top priority from the caregivers' perspective. This is because many caregivers consider other competing tasks to be more important; and believing that oral care is only a form of personal care equivalent to cutting hair, shaving or cutting fingernails (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015). This barrier has the greatest impact when the caregivers face challenges to complete their duties due to time constraints (Yeung and Chui, 2010; Coker *et al.*, 2017a). In such situations, the caregivers usually focus on other aspects of dependent adults' care that they consider to be life-preserving and to their understanding positively contributing to the dependent adults' general health (Hallberg and Klingberg, 2007; Yeung and Chui, 2010; Horne *et al.*, 2015).

The caregivers' lack of knowledge and skill about oral health and care was attributed to the inadequacy of educational courses and programmes in the undergraduate stage, as well as in the workplace (Wårdh *et al.*, 2000; Yeung and Chui, 2010; De Visschere *et al.*, 2015). However, even though courses about oral health and care are available for professional caregivers in several developed countries (Wårdh *et al.*, 2012; Gopalakrishnan *et al.*, 2019), many of these courses have been criticised for not focusing on the technical aspects of the oral care, as well as not explaining the rationale behind oral care practices (Yeung and Chui, 2010; De Visschere *et al.*, 2015; Horne *et al.*, 2015; Coker *et al.*, 2017a). Thus, demand for better courses is a common theme found in the contemporary literature (Dharamsi *et al.*, 2009; Wårdh *et al.*, 2012; De Visschere *et al.*, 2015; Gopalakrishnan *et al.*, 2019).

Lastly, the attitude of caregivers toward oral health and care could be a barrier for providing excellent oral care to dependent adults. It has been reported that caregivers who do not consider oral health and care as a personal priority would tend to place less value on providing oral care for dependent adults (Dharamsi *et al.*, 2009; Wårdh *et al.*, 2012; De Visschere *et al.*, 2015; Coker *et al.*, 2017a; Smith and Thomson, 2017). In addition, caregivers who perceive oral care to be a repulsive and disgusting task in general may not tend to undertake it for dependent adults (Dharamsi *et al.*, 2009; De Visschere *et al.*, 2015). In fact, many of those caregivers reported that they would prefer to perform other tasks such as cleaning up after bowel movements or attending to urinary incontinence accidents above conducting oral care for dependent adults (Dharamsi *et al.*, 2009).

There are several barriers for providing oral care for dependent adults that are related to their environment. For example, tools necessary for undertaking regular oral care such as toothbrushes and mouth rinse may not be easily available, which in many cases has been shown to be a result of financial constraints (Yeung and Chui, 2010; Gopalakrishnan *et al.*, 2019). Another environment-related barrier is the limitation in staff, which could reduce the time available to provide adequate oral care (Wårdh *et al.*, 2000; Yeung and Chui, 2010; De Visschere *et al.*, 2015; Smith and Thomson, 2017). This barrier was reported to be relevant to both hospitals and care home settings (De Visschere *et al.*, 2015; Horne *et al.*, 2015). However, some caregivers believed that the staff shortage and the limited time to provide oral care are only excuses from caregivers who lack prioritisation or time management skills (De Visschere *et al.*, 2015).

Oral care practice is not universally embedded in the policies of many hospitals and care homes, and thus, this could be another barrier that prevents providing adequate oral care for dependent adults. This is because oral care in these settings is usually reactive rather than proactive or integrated into overall care (Smith and Thomson, 2017). In fact, it has been reported that even when oral care practice is part of the setting's policies, it may not be appropriately implemented due to other barriers described previously (Smith and Thomson, 2017). This was reported from a wide variety of countries such as Australia, New Zealand and Canada (Hearn and Slack-Smith, 2016; Coker *et al.*, 2017a; Smith and Thomson, 2017). A lack of policy could negatively shape the work routine, access to oral care supplies and lack of communication between the caregivers (Yeung and Chui, 2010; Coker *et al.*, 2017a). A lack of policy may also result in not labelling the dependent adults' toothbrushes and absence of a standard storage location, which lead to loss or inappropriate use of oral care tools (De Visschere *et al.*, 2015). Inadequate policy was also perceived to be responsible for the limited collaboration between the dental professionals and the caregivers, which led to caregivers feeling that they are not adequately supported to provide optimal oral care to dependent adults (Wårdh *et al.*, 2000; De Visschere *et al.*, 2015; Hearn and Slack-Smith, 2016).

Barriers to dental treatment

Access to dental treatment might be restricted for dependent adults. There are many barriers related to the dependent adults, their caregivers and their environment, which may contribute to this difficulty in access. For example, many dependent adults lack the ability to initiate the treatment-seeking process because of the decline in their communication ability or in their autonomy to make such decisions (Hearn and Slack-Smith, 2016; Gopalakrishnan *et al.*, 2019). In addition, older people who become dependent may be less inclined to pursue dental treatment. This could be attributed to the phenomenon known as "self-agism", in which adults after dependency tend to accept their oral health decline and consider it as part of their ageing process (Smith and Thomson, 2017). Furthermore, as dependency could negatively impact the mood of dependent adults, this may adversely affect their willingness to seek recommended dental treatment (Hearn and Slack-Smith, 2016). Lastly, many dental professionals have raised concerns about the compliance and cooperation of dependent adults during the delivery of dental treatment (Scrine *et al.*, 2019).

The limited availability of domiciliary oral health services is another barrier that may restrict dependent adults' access to dental treatment (Hearn and Slack-Smith, 2016; Smith and Thomson, 2017). The limited availability of this service can be attributed to the unwillingness of dental professionals to provide it (Hearn and Slack-Smith, 2016). This attitude was suggested to be due to the small margin of profit attained from providing such service (Smith and Thomson, 2017). In addition, there were concerns in the literature regarding the required skills and knowledge of dental professionals to provide dental treatment for dependent adults (Smith and Thomson, 2017). The difficulty to provide dental treatment was suggested to stem from the fact that dependent adults usually experience comorbidities and may not always be cooperative during the treatment (Hearn and Slack-Smith, 2016; Smith and Thomson, 2017). These concerns about dental professionals' skills and knowledge were also reported by dependent adults themselves (Blaizot *et al.*, 2017).

Environment-related factors can contribute to preventing access to professional dental care. For example, policies in hospitals and care homes do not usually support referring dependent adults for dental treatment or regular check-ups (Smith and Thomson, 2017; Gopalakrishnan *et al.*, 2019). This is manifested in the lack of funding for these procedures (Smith and Thomson, 2017; Gopalakrishnan *et al.*, 2019). In addition, these policies might be responsible for not supporting caregivers to accompany dependent adults during their visit to the dental clinic (Hearn and Slack-Smith, 2016). Another environment-related barrier is the lack of transportation for dependent adults to go to the dental clinic due to infrastructures inadequacy. For example, many dental clinics are not wheelchair friendly (Smith and Thomson, 2017; Gopalakrishnan *et al.*, 2019). In addition, these dental clinics may not have a hoist to transfer dependent adults to and from the dental chair (Gopalakrishnan *et al.*, 2019).

2.3.3 Measuring oral health for dependent adults

The last section discussed many barriers that can prevent dependent adults from experiencing satisfactory oral health status. Those barriers were related to the dependent adults themselves, their caregivers and their environment. However, one of the most frequently reported barriers was the caregivers' lack of knowledge and skill about oral health and oral care (Göstemeyer *et al.*, 2019). This lack of knowledge and skill can be manifested in the inability of the caregivers to easily detect oral health problems in those who are dependent on them for personal care (Yoon and Steele, 2012; De Visschere *et al.*, 2015; Horne *et al.*, 2015; Smith and Thomson, 2017). It can also be manifested in the caregivers feeling unable to undertake the correct actions to resolve obvious oral health problems (De Visschere *et al.*, 2015; Horne *et al.*, 2015). This may explain why formal caregivers, as well as medical and dental professionals, have voiced a need for an oral health measurement instrument that can be used to inform the development of oral health care plans for dependent adults (Hijii, 2003; Horne *et al.*, 2015; Smith and Thomson, 2017; Andersson *et al.*, 2019). They believed that utilising such instruments will not only help in identifying oral health problems but will also help in monitoring the quality of oral care provided, which could then encourage overall improvement in the quality of daily oral care (Dharamsi *et al.*, 2009; De Visschere *et al.*, 2015; Horne *et al.*, 2015; Smith and Thomson, 2017).

To address this clinical need for measuring oral health, several instruments have been developed for use by non-dental caregivers to guide establishing oral care plans for dependent adults (Chalmers and Pearson, 2005). The Brief Oral Health Status Examination Index (BOHSE) is an example of these measurement instruments and it was developed to be used by staff in care homes (Kayser-Jones *et al.*, 1995). It was modified 10 years later to improve its feasibility and usability (Chalmers *et al.*, 2005). Another measurement instrument is The Holistic and Reliable Oral Assessment Tool (THROAT) that was developed to be used in stroke wards (Dickinson *et al.*, 2001). Even though these measurement instruments have existed for several decades, they have not been widely adopted in daily clinical practice. For example, in a cross-sectional study investigating oral care in stroke units in Manchester, only two units out of 11 reported using an official oral health measurement instrument (Horne *et al.*, 2015). In fact, most of the caregivers who were interviewed in qualitative studies about oral care for dependent adults, assessed the oral health of dependent adults by either relying on the verbal cues from the dependent adults or subjectively evaluating the dependent adult's oral cavity (Yeung and Chui, 2010; Wårdh *et al.*, 2012; Horne *et al.*, 2015; Coker *et al.*, 2017a).

Several factors could explain why the previously mentioned measurement instruments have not been widely used in the clinical setting. Firstly, none of these instruments were developed based on an evidence-based conceptual model of oral health for dependent adults. Notably, the literature still lacks a scientifically based conceptual model that describes the construct of oral health and its interrelationships, which also takes into consideration both dependent adults' and their caregivers' perspectives and views. Establishing such a model has been suggested to be paramount to develop oral health measurement instruments that can detect the most important aspects of oral health from the dependent adults' perspectives, and therefore have a greater potential to improve the quality of care provided to them (Philpot *et al.*, 2018). Another potential benefit from guiding the development of the oral health measurement instruments with such a conceptual model is that it will help in developing measurement instruments whose items are grouped into correct domains (Rothman *et al.*, 2007). Thus, assessments performed by such instruments would result in better evaluations and more accurate scoring of the oral health status in the dependent adults, and therefore actions or interventions that are undertaken based on these scorings should also be more effective (Rothman *et al.*, 2007).

Another limitation that might prevent a wide utilisation of oral health measurement instruments for the dependent adult is the lack of a systematic review that comprehensively and critically appraised the methods and performances of this type of measurement instruments. Because the measurement properties (i.e. validity and reliability) of health-related measurement instruments are usually assessed in more than one study, it might be difficult for caregivers to make a sound judgment about the best available oral health measurement instrument that could guide the oral care planning for dependent adults. Thus, there is a need to conduct a systematic review that identifies this type of oral health measurement instruments. Based on the findings of this systematic review, caregivers could make an evidence-based decision about the best available oral health measurement instruments that could be used directly or modified and adapted to guide oral care planning for dependent adults (De Vet *et al.*, 2011, p. 275).

Lastly, even if the oral health measurement instruments for the dependent adults are supported by strong evidence regarding their measurement properties, they may not be successfully implemented if they have problems relative to their feasibility and usability (Nilsen, 2015). Within this current literature review, none of the identified studies explored the feasibility and usability of oral health measurement instruments for dependent adults. Only a limited number of studies have briefly considered this topic (Kayser-Jones *et al.*, 1995; Chalmers *et al.*, 2005; Smith and Thomson, 2017). According to healthcare implementation theories, many factors other than the quality of evidence supporting the instrument's measurement properties can determine its implementation and application success (Moullin *et al.*, 2015). These factors can be related to the measurement instrument itself, the users (i.e. caregivers), the receivers (i.e. dependent adults) and the application environment (i.e. homes, care homes or hospitals) (Flottorp *et al.*, 2013; Atkins *et al.*, 2017). Thus, for oral health measurement instruments to be successfully implemented and applied for dependent adults, there is a need to identify and explore these factors.

2.3.4 Conclusion

Dependent adults have been reported to experience a plethora of oral health problems. These include poor oral hygiene, dental caries, periodontal diseases, other mucosal lesions and orofacial pain. These reports demonstrated that dependent adults usually experience these problems at a higher frequency than independent adults. In addition, they showed a clear association between disability (i.e. major determinant of care dependency) and oral health decline. These oral health problems can be attributed to a number of barriers that prevent optimal oral care and dental treatment to be provided for dependent adults. Beside dependent adults' refusal of oral care and dental treatment, caregivers' limited knowledge and skill about oral health and care is the most frequently reported barrier in the literature. Utilising oral health measurement instruments may help the caregivers overcoming the limitation in their knowledge. While this section of the literature review revealed that several oral health measurement instruments have been developed to inform oral care planning for dependent adults, none of them has been widely used in clinical settings. Several factors explaining the limited implementation of these instruments have been discussed. These factors, therefore, need to be considered when designing the programme of work for this project.

2.4 Summary Conclusions

This literature review covered three essential topics regarding this PhD thesis. First, the definition and measurement of oral health were explored. This allowed for the adoption of a suitable definition to guide the search process during the literature review and to define the phenomenon of interest in the systematic reviews' protocols. In addition, this section of the literature review revealed the complexity of the theoretical bases underpinning instruments measuring oral health, which may help guiding the development of a new oral health measurement instrument.

The second topic reviewed in this chapter was the phenomenon of dependency in adults. It showed that dependency on care is a social construct that does not represent a personal attribute of individuals, but a social relationship between them. It can promptly occur because of physical or mental conditions leading to disability. However, care dependency can develop gradually in older adults due to frailty or comorbidity. Dependency in adults represents an ongoing and increasing problem in the general population. This is demonstrated by the increase in the prevalence of dependency among adults over the last decades, as well as the expected growth in the upcoming years. Thus, more research is needed to further our understanding of many aspects that are still not well understood about dependent adults, their oral health and their care.

Finally, the literature review explored oral health in dependent adults. It demonstrated that oral health could significantly deteriorate after dependency. This decline can be manifested by poor oral hygiene, dental decay and periodontal diseases. Many causes could explain this deterioration in oral health, which have been classified into barriers to oral care and dental treatment. Measuring oral health to guide oral care planning for dependent adults has the potential to positively contribute to improving their oral health. Steps that need to be undertaken to develop such an instrument was also reviewed in this section.

Chapter 3. Aim, Objectives, and Programme of Work

3.1 Aim

To investigate oral health assessment measures that can facilitate the establishment of oral care planning for dependent adults.

3.2 Objectives

1. To establish a conceptual model of oral health in dependent adults that defines the construct of oral health and describes its interrelationships based on dependent adults' and their caregivers' experiences and views.
2. To systematically identify measurement instruments that measure oral health (or orofacial pain) in dependent adults and evaluate these instruments' measurement properties, interpretability and feasibility.
3. To explore and understand service providers' experiences and views about oral health in dependent patients (after a stroke), as well as implementation issues and potential barriers for measuring oral health in these patients.

3.3 Programme of Work

The three objectives were addressed sequentially by conducting three separate studies:

1. A qualitative evidence synthesis that systematically explored the relevant literature examining dependent adults' and their caregivers' experiences and views about oral health to develop an empirical conceptual model of oral health in dependent adults.
2. A quantitative systematic review that identified and critically appraised the previously published oral health (and orofacial pain) measurement instruments for dependent adults.
3. A qualitative study that interviewed the service providers of post-stroke patients whose roles and duties are relevant to the patients' oral health and care.

Chapter 4. A Qualitative Evidence Synthesis Establishing an Empirical Conceptual Model of Oral Health in Dependent Adults—A Systematic Review

4.1 Introduction

To develop a valid oral health measurement instrument for dependent adults, there is a need to establish a scientifically based conceptual model that describes the construct of oral health in dependent adults and its interrelationships, and that takes into consideration both dependent adults' and their caregivers' perspectives and views (De Vet *et al.*, 2011, p. 157). Guiding the development of the measurement instrument with a scientifically based conceptual model would help in developing an instrument whose items are grouped into correct domains (Rothman *et al.*, 2007). Thus, assessments that are done by such an instrument would result in better evaluations and accurate scorings of oral health status in dependent adults, and therefore actions or interventions that are undertaken based on these scorings should also be more effective (Rothman *et al.*, 2007). In addition, including dependent adults' views during the conceptual model development would help in the development of an instrument that detects the most important aspects of oral health from their perspectives, and therefore have a greater potential to improve the quality of care provided to them (Philpot *et al.*, 2018).

A conceptual model should be established utilising qualitative methods because they represent the best scientific approach to understanding meaning and experience of people's lives (Fossey *et al.*, 2002). There are a number of advantages to undertaking a systematic review of qualitative studies (qualitative evidence synthesis) over conducting a single primary qualitative study. First, qualitative evidence synthesis has the potential to provide more perspectives than a single primary qualitative study, and therefore could present various possible contradictory viewpoints that might not be captured by a single study (Carroll, 2017). In this way, a qualitative evidence synthesis could go beyond the findings of primary qualitative studies, and therefore produce conclusions that have greater understanding and deeper interpretation of the phenomenon being investigated (Pope *et al.*, 2006; Carroll, 2017). Dependent adults represent a diverse population, it would therefore be extremely difficult from a logistical perspective to conduct a primary qualitative study that captures this diversity (Wilkin, 1987). Thus, a qualitative evidence synthesis was selected to establish a conceptual model that would aim to describe the phenomenon of oral health in dependent adults.

4.2 Aim

To establish a conceptual model of oral health in dependent adults that defines the construct of oral health and describes its interrelationships based on dependent adults' and their caregivers' experiences and views.

4.3 Methods

4.3.1 Qualitative evidence synthesis methods

Qualitative evidence synthesis is a systematic review of primary qualitative studies, which is usually undertaken either as a stand-alone review or as part of a mixed method systematic review (Flemming *et al.*, 2019). There are numerous methods that have been described in the literature for undertaking qualitative evidence synthesis. These methods can be described on a continuum between an integrative (aggregative) and interpretive (configurative) approaches (Booth *et al.*, 2016). Integrative methods are deductive in nature and aim to simply summarise and aggregate qualitative data from primary studies into themes. These integrative methods are usually undertaken when themes and concepts are clearly described in the primary research (Flemming *et al.*, 2019). Framework synthesis is an example of an integrative method (Noyes *et al.*, 2018a). In contrast, interpretive methods are inductive in nature and aim to generate new concepts and theories that are grounded in the data in the identified primary studies. These methods are usually undertaken when there is a need to generate new explanations and theories about a phenomenon (Flemming *et al.*, 2019). An example of interpretive methods to undertake qualitative evidence synthesis is meta-ethnography (Noyes *et al.*, 2018a). Descriptions of the most used methods for qualitative data synthesis are presented below.

Meta-ethnography is one of the most prevalent methods that have been utilised in systematic reviews of qualitative studies (Booth *et al.*, 2016, p. 229). It was first described in the literature by Noblit and Hare (1988). This method is one of the most interpretive approaches that can be used in qualitative evidence synthesis (Flemming *et al.*, 2019). It aims to translate concepts across primary qualitative studies through different means that include reciprocal translation, refutational synthesis and line of argument synthesis (Noblit and Hare, 1988). Reciprocal translation is undertaken when the primary qualitative studies are about similar things and it is undertaken by translating each study into the terms (metaphors) of others and establishing the area where the studies are sharing common overarching themes and concepts (Noblit and

Hare, 1988, p. 38). On the other hand, refutational synthesis is undertaken when the primary qualitative studies implicitly or explicitly are refuting each other (Noblit and Hare, 1988, p. 47). Refutational synthesis takes into consideration the implied relationships between refuting concepts, and therefore extensively analyses these relationships and then incorporates them into the final synthesis (Noblit and Hare, 1988, p. 48). Finally, the line of argument synthesis is undertaken to establish an understanding of the whole phenomenon based on selective studies by identifying where different primary qualitative studies are contributing to the same line of thought through inference (Noblit and Hare, 1988, p. 62).

Thematic synthesis method is an umbrella term that includes different approaches that are very similar to each other in their main steps (Flemming *et al.*, 2019). These approaches are based on the thematic analysis which is widely used to analyse qualitative data in primary studies (Booth *et al.*, 2016, p. 226). Thematic synthesis is undertaken in a number of steps. First, free line-by-line coding of the findings of primary qualitative studies is undertaken (Thomas and Harden, 2008). Then, based on the similarities between the different codes, they are combined together into descriptive themes (Thomas and Harden, 2008). Finally, depending on the depth and richness of qualitative data in the primary studies, the analysis can be taken further to establish analytical themes that can go beyond the findings of the primary studies (Thomas and Harden, 2008).

Framework synthesis method is located more towards the integrative side of the qualitative evidence synthesis continuum (Booth *et al.*, 2016, p. 227). This method is based mainly on the framework analysis that is used in primary qualitative studies (Bryman and Burgess, 2002, p. 177). It is advisable to use this method when there is a well-established conceptual model or framework that can be used as an *a priori* framework (Bryman and Burgess, 2002, p. 179). The concepts in the *a priori* framework are used for coding findings from the primary qualitative studies (Bryman and Burgess, 2002, p. 180). The rationale behind this method is that it offers an approach to organising and analysing large amounts of qualitative data in a highly structured and systematic manner (Flemming *et al.*, 2019). Another suggested advantage of this method is being time efficient compared to other approaches (Flemming *et al.*, 2019).

"Best fit" framework synthesis method has been developed to capture the inherent advantages of both thematic synthesis method and framework synthesis method (Carroll *et al.*, 2011). Unlike the framework synthesis method, the existence of a well-established conceptual model or framework is not necessary (Carroll *et al.*, 2011). A good enough framework can be used in the start of the synthesis, and later data that are not captured by the *a priori* framework to be analysed using thematic analysis (Carroll *et al.*, 2011). A detailed description of this method follows below.

4.3.2 Study design

This qualitative evidence synthesis utilised a "best fit" framework synthesis method where most of the data extraction and coding were done using an *a priori* framework while the remaining evidence that was not captured by the *a priori* framework was coded using thematic analysis (Carroll *et al.*, 2011; Carroll *et al.*, 2013). This method of synthesis allows for the testing of and building on existing models and theories about a certain phenomenon on a relatively different population (Carroll *et al.*, 2013), and may therefore help to understand the differences in regard to oral health perceptions between dependent adults and the general population. In addition, the "best fit" framework synthesis method has been suggested to be used by less experienced reviewers because it gives them the chance to perform a relatively simpler and easier coding using an *a priori* framework and then as they build up their experiences, they could perform the thematic analysis for the remaining evidence (Booth *et al.*, 2016, p. 263). Another advantage of this method of synthesis is being more rapid than other synthesis methods (Carroll *et al.*, 2011). Furthermore, it may provide a more transparent and systematic way of synthesising data when compared with other methods, and thus improving reproducibility in research and reducing potential biases (Carroll *et al.*, 2011; Booth and Carroll, 2015a). However, the simplified and fast paced nature of this method may lead to an increased risk of forcing unrelated data into the framework (Carroll *et al.*, 2013). To reduce the possibility of false coding, it was suggested that coding be done by two independent reviewers (Carroll *et al.*, 2013). In addition, another potential disadvantage is the risk of not being able to identify a suitable framework for data extraction and coding, simply because no suitable frameworks exist in the scientific literature (Noyes *et al.*, 2018a).

Two separate systematic searches were completed within this qualitative evidence synthesis. The first search aimed to identify relevant frameworks, theories and conceptual models that could be used to establish the *a priori* framework. The second systematic search aimed to identify primary qualitative studies that could provide data to be synthesised for this review research question.

The search process was continuously documented. This involved documenting the interfaces that were used to search the databases, the date of search and the search strategies used. The titles of articles identified by the search process were recorded. The titles of included studies from screening the abstracts were recorded. The titles of articles that were excluded after screening the full texts were recorded, along with the reasons for exclusion.

This qualitative evidence synthesis was reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Statement (Tong *et al.*, 2012). The ENTREQ Statement consists of 21 items that are derived from five main categories (Tong *et al.*, 2012). ENTREQ is currently the only available reporting guideline for qualitative evidence synthesis, which is intended to improve transparency and clarity of reporting style, and thus it may help the end reader to comprehend better the methods used and findings reported in qualitative evidence synthesis (Tong *et al.*, 2012; Flemming *et al.*, 2018). However, it must be noted that the ENTREQ statement has been criticised for lacking strong evidence to support its validity (Flemming *et al.*, 2018).

4.3.3 Protocol and registration

The objectives and methods of this study were documented in a protocol before conducting the study to reduce potential *post hoc* biases. The protocol was registered in the International Prospective Register of Systematic Reviews (PROSPERO) database and the registration number is CRD42018086191 (BaHammam *et al.*, 2018).

4.3.4 Establishing the a priori framework

The BeHEMoTh (i.e. “Be” Behaviour of interest, “H” Health context, “E” Exclusions, and “MoTh” Models or Theories) search procedure provides a systematic and transparent method for identifying frameworks, models or theories that could be used to establish the *a priori* framework (Booth and Carroll, 2015b). The BeHEMoTh search procedure identifies relevant frameworks, models and theories from two sources, which are electronic bibliographic databases and internal reference management database of the included primary qualitative studies. Even though the team who developed this procedure admitted that their procedure still requires rigorous testing to establish its validity, it was the best alternative identified to establish an *a priori* framework. This is mainly because this procedure is more systematic and transparent than an arbitrary selection made by the research team of a model or a framework to establish the *a priori* framework (Booth and Carroll, 2015b). In addition, this procedure could close a potential gap between the theoretical and empirical literature, which is especially true if only frameworks, models and theories are identified and selected from those mentioned in the primary qualitative studies (Booth and Carroll, 2015b).

Electronic bibliographic database searches

Four bibliographic databases were searched: MEDLINE was searched via Ovid (1946 to November Week 2, 2017); Embase was searched via Ovid (1974 to November Week 2, 2017); PsycINFO was searched via Ovid (1976 to November Week 2, 2017); and CINAHL was searched via EBSCO (1986 to November Week 2, 2017).

The BeHEMoTh framework was utilised to develop the search strategies for each database, as well as formulating inclusion and exclusion criteria. That is: Behaviour of interest - oral health; Health context - dependency or being dependent; Exclusion - non-theoretical model or technical model, or studies published in languages other than English; and Models or Theories - full text studies exploring, testing or creating frameworks, models or theories. A detailed description of the MEDLINE search strategy is shown in Table 4.1. The electronic database searches were restricted to the English language for feasibility reasons.

Internal reference management database searches

A search was conducted for the terms “theor*”, “concept*”, “framework*” or “model*” in the titles and abstracts of the articles identified during the electronic database searches for primary qualitative studies (i.e. studies identified in the second systematic search), and in the full text of potentially eligible ones. A list was created by two independent reviewers, Fahad BaHammam (FB) and Jamal Akhil (JA), of cited articles describing models which were explicitly linked either to the behaviour of interest (i.e. oral health) or the health context (i.e. dependency or being dependent).

Next, searches were conducted using Scopus and Web of Science for the names of the identified models in the previous step in combination with keywords representing oral health to identify more relevant frameworks, theories and models.

Then, citation searches were performed using Scopus and Web of Science for all the identified key articles (i.e. articles describing relevant models) combined with keywords for oral health, to identify frameworks, theories or models that might have been missed during the previously described searches.

Selection process

Two reviewers (FB & JA) independently screened the titles and abstracts of identified studies from the electronic bibliographic database searches and from internal reference management database searches to select studies describing frameworks, theories or models that are relevant to oral health. When there was doubt regarding the eligibility of a study at this stage, it was selected and the final decision was made after screening the full text.

The full texts were retrieved for all studies identified as potentially eligible from screening their titles and abstracts and they were subjected to the same inclusion/exclusion evaluation process to determine the relevant studies to be included. Disagreement was resolved through discussion between the two reviewers (FB & JA), and with one of the supervisors Dr Rebecca Wassall (RW) when agreement could not be reached.

Fifteen studies were included that have described conceptual models relevant to oral health. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram in Figure 4.1 that was adapted from Moher *et al.* (2009) summarises the screening and selection processes.

Data extraction and synthesis

Because more than one model was identified, a decision was made to modify and amalgamate these models using thematic analysis to produce the *a priori* framework because all models were equally relevant, and no scientific or empirical evidence was identified to choose one model over the others.

Because not all the 15 studies described novel conceptual models of oral health and some of them were only representing a slight modification from another, these studies have been classified into six groups where each group describes the same conceptual model. The main characteristics of the 15 studies included are illustrated in Table 4.2.

Concepts that formed the conceptual models and their definitions were extracted from the original studies for each group. A thematic analysis was then performed by identifying commonalities and differences among identified models' concepts in all six groups and they were reduced to their key elements or variables to establish different codes that formed the new meta-framework. Each code was then defined based on the findings from the original papers to increase the reliability of the coding and data extraction process between the two independent reviewers, as well as increasing the overall rigour of the synthesis (Carroll *et al.*, 2011). The newly established meta-framework consisted of 13 different codes with one additional code for data that were not captured by the meta-framework. The names of the codes and their definitions are shown in Table 4.3.

1	Oral Health/ or Mouth Diseases/ or Tooth Diseases/ or exp Oral Hygiene/ or exp Facial Pain/ or (dent* adj1 disease*).mp. or (oral adj1 disease*).mp. or (mouth adj1 disease*).mp. or (facial adj1 disease*).mp. or (t??th adj1 disease*).mp. or (orofacial adj1 pain).mp. or (dent* adj1 pain).mp. or (t??th adj1 pain).mp. or (oral adj1 pain).mp. or (mouth adj1 pain).mp. or (facial adj1 pain).mp. or (dent* adj1 health).mp. or (oral adj1 health).mp. or (mouth adj1 health).mp. or (facial adj1 health).mp. or (t??th adj1 health).mp.
2	Frail Elderly/ or exp Disabled Persons/ or Vulnerable Populations/ or exp Intensive Care Units/ or exp Residential Facilities/ or Caregivers/ or Home Health Aides/ or Adult Day Care Centers/ or Disable*.mp. or caregiver*.mp. or (Dependent adj1 adult*).mp. or (Dependent adj1 elder*).mp. or (Dependent adj1 person*).mp. or (Dependent adj1 individual*).mp. or (Dependent adj1 patient*).mp. or Frail*.mp.
3	(Model* or theor* or framework* or concept*).mp.
4	(Regression or integrative model or integrative care model or economic or Markov or animal).mp.
5	1 and 2 and 3
6	5 not 4
7	limit 6 to English language

Table 4.1: MEDLINE search strategy to establish the *a priori* framework.

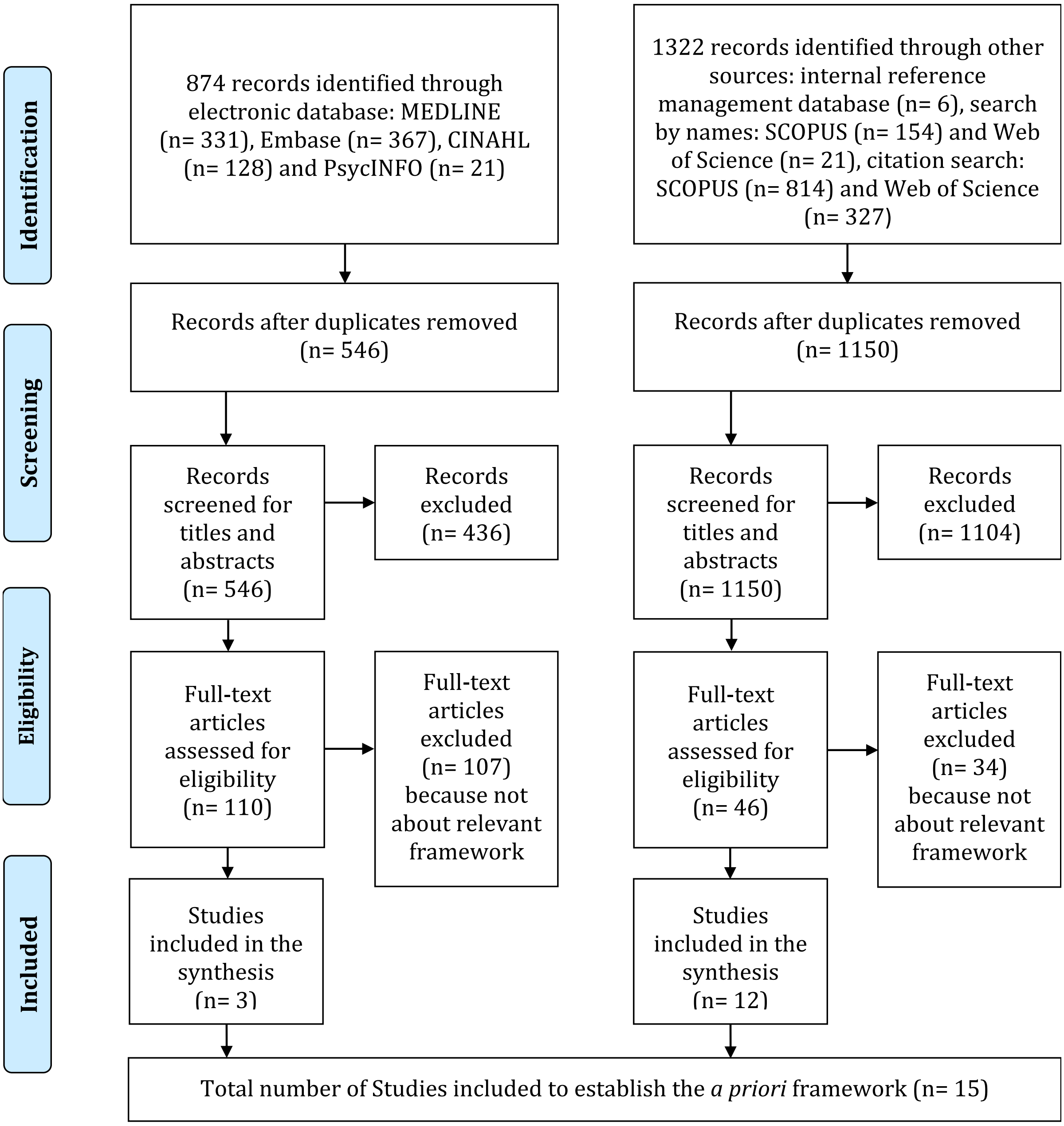

Figure 4.1: PRISMA flow diagram for retrieval, screening and selection processes to establish the *a priori* framework.

Group	Authors	Year	Country	Population	Construct
1	Locker	1988	Canada	Not specified	Oral health
	Nuttall *et al.*	2006	UK & Australia	Adults	Oral health
	Baker	2007	UK	Adults, edentulous older people & xerostomia patients	Oral health
	Masood *et al.*	2015	Malaysia	Patients with malocclusion	Oral health
2	Wilson and Cleary	1995	USA	Not specified	Health Related Quality of Life
	Locker and Gibson	2005	Canada & UK	Older people	Oral Health Related Quality of Life
	Baker *et al.*	2007	UK	Patients with xerostomia	Oral Health Related Quality of Life
	Baker *et al.*	2008	UK	Housebound edentulous older people	Oral Health Related Quality of Life
3	Gilbert *et al.*	1998	USA	Adults	Oral health
	Åstrøm *et al.*	2010	Sweden & Norway	Older people	Oral health
4	WHO	2001	Worldwide	Not specified	General health
	Ekbäck *et al.*	2012	Sweden & Norway	Older people	Oral health
5	MacEntee *et al.*	1997	Canada	Older people	Oral health
	MacEntee	2006	Canada	Older people	Oral health
6	Brondani *et al.*	2007	Canada	Older people	Oral health

Table 4.2: Main characteristics of the 15 studies included to establish the *a priori* framework.

Code's name	**Definition**
Health condition	Conditions that affect oral health by changes in the cell, organ structure or organ function such as disease, disorder, injuries and trauma.
Structure	Anatomical part of the oral cavity. Data about any problem in the structure such as significant deviation or loss from generally accepted population standards will be coded using this code.
Function	Any physiological function of the oral cavity. Data about restrictions in the function customarily expected of the body or its component organs or systems will be coded using this code.
Hygiene	The concept of a clean mouth and the process of keeping the mouth clean.
Symptoms	Patient's perception of an abnormal physical, emotional or cognitive state that is not directly observable.
Activity	Execution of a task or action by an individual. Data about lack of ability or difficulties an individual may have in executing activities will be coded using this code.
Self-rated oral health	Subjectively defined overall oral health.
Participation	Involvement in life situation. Data about problems an individual may experience in involvement in life situation will be coded using this code.
Overall quality of life	Subjective well-being of how happy and/or satisfied individuals are with their life.
General health	State of physical, mental and social well-being.
Death	Clear concept and therefore no need for definition.
Personal factors	Particular background of an individual's life and living, comprising features of the individual that are not part of a health condition or health states.
Environmental factors	Make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals.
Other	Data not captured by the above codes that need to be coded against independently generated codes.

Table 4.3: Meta-framework for oral health.

4.3.5 Criteria for considering primary qualitative studies

SPIDER (i.e. Sample, Phenomena of Interest, Design, Evaluation and Research type) is a search strategy tool that has been developed to be used in qualitative systematic reviews (Cooke *et al.*, 2012). It has been shown to be more effective than other tools such as PICOS (i.e. Participants, Interventions, Comparators, Outcomes and Studies) in retrieving relevant and eligible studies in qualitative systematic reviews (Cooke *et al.*, 2012). Thus, it was adopted in this qualitative evidence synthesis to inform the development of the research question, the screening criteria used for selecting studies and for the development of the search strategies. The inclusion and exclusion criteria for selecting primary qualitative studies based on the SPIDER format are shown in Table 4.4.

4.3.6 Search methods for identification of primary qualitative studies

Sampling in qualitative research is mainly done using purposive and theoretical sampling strategies that aim to select information-rich cases who can allow an in-depth understanding of the phenomenon of interest, rather than establishing empirical generalisations (Gentles *et al.*, 2015). Thus, many methodologists advocated utilising this strategy, which is iterative in nature, when identifying and selecting studies for qualitative evidence synthesis (Benoot *et al.*, 2016; Ames *et al.*, 2019). This point of view is also supported by the fact that if there is a large number of included eligible studies, the huge volume of data may only allow to undertake a superficial analysis (Benoot *et al.*, 2016; Ames *et al.*, 2019).

It has been argued, however, that it is impossible to establish the population of studies from which a purposive sample is to be selected without identifying all relevant studies (Atkins *et al.*, 2008). In addition, in contrast to people, scientific studies are only published if they present novel findings, and thus excluding eligible studies from the synthesis can potentially lead to missing important insights (Dixon-Woods *et al.*, 2006). Furthermore, it is difficult to determine the saturation point during the synthesis without having access to the original data (Atkins *et al.*, 2008). Therefore, a pre-planned and comprehensive search method has been utilised in this evidence synthesis while identifying and selecting eligible studies.

Electronic bibliographic database searches:

Four electronic bibliographic databases were searched on the 21st of November 2017 and were later updated on the 3rd of July 2019:

- MEDLINE via Ovid (1946 to June Week 4, 2019)
- Embase via Ovid (1974 to June Week 4, 2019)
- PsycINFO via Ovid (1976 to June Week 4, 2019)
- CINAHL via EBSCO (1986 to June Week 4, 2019)

A detailed search strategy was developed for the MEDLINE database using relevant keywords and Medical Subject Headings (MeSH) terms by the research team and it was reviewed and modified by a librarian from Newcastle University library. It was translated and revised appropriately for the other databases considering the differences in thesaurus terms and syntax rules. The electronic database searches were restricted to the English language and studies about children were excluded. A detailed description of the MEDLINE search strategy is shown in Table 4.5.

Other methods used to identify relevant studies:

A citation search of the included studies was carried out using Scopus and Web of Science citation indices. In addition, reference lists were manually searched for the included studies. Furthermore, on the 15th May 2018 the following sources of grey literature were searched for eligible studies: Open Access Theses and Dissertations (OATD) and OpenGrey.

4.3.7 Selection process

The selection process for primary qualitative studies mirrored that for selecting studies during establishing the *a priori* framework, which was described in Section 4.3.4. Briefly, titles and abstracts were independently screened by two reviewers (FB & JA) before reviewing the full texts based on predetermined inclusion and exclusion criteria. Disagreement was resolved through discussion between the two reviewers and with one of the supervisors (RW) when necessary.

	Inclusion criteria	Exclusion criteria
Sample	• Dependent adult: o 18 years or older o Need or receive support/assistance due to a reduction in mental capacity or physical capability • Caregiver of dependent adult (i.e. caregiving ranges from daily routine care to active treatment and the caregiving is either provided by a health care professional or non-professional caregiver) • Family caregiver of a dependent adult	• Dependent person who is less than 18 years old • Population of interest is independent
Phenomenon of interest	• Oral health in dependent adults • Study providing qualitative data about oral health in dependent adults even when its main aim is different from this review's aim	• Not about oral health in dependent adults
Design	• Empirical qualitative study (i.e. observation, focus group and interview) or mixed method study	• Quantitative study
Evaluation	• Qualitative data relating to experiences and views of oral health in dependent adults.	• Study without qualitative data
Research type	• Study published in the English language • No restrictions on the setting where the study has been undertaken • No restrictions on the publication date	• Study published in languages other than English

Table 4.4: Inclusion and exclusion criteria for selecting primary qualitative studies.

1	Oral Health/ or Mouth Diseases/ or Tooth Diseases/ or exp Oral Hygiene/ or exp Facial Pain/ or (dent* adj1 disease*).mp. or (oral adj1 disease*).mp. or (mouth adj1 disease*).mp. or (facial adj1 disease*).mp. or (t??th adj1 disease*).mp. or (orofacial adj1 pain).mp. or (dent* adj1 pain).mp. or (t??th adj1 pain).mp. or (oral adj1 pain).mp. or (mouth adj1 pain).mp. or (facial adj1 pain).mp. or (dent* adj1 health).mp. or (oral adj1 health).mp. or (mouth adj1 health).mp. or (facial adj1 health).mp. or (t??th adj1 health).mp.
2	Frail Elderly/ or exp Disabled Persons/ or Vulnerable Populations/ or exp Intensive Care Units/ or exp Residential Facilities/ or Caregivers/ or Home Health Aides/ or Adult Day Care Centers/ or Disable*.mp. or caregiver*.mp. or (Dependent adj1 adult*).mp. or (Dependent adj1 elder*).mp. or (Dependent adj1 person*).mp. or (Dependent adj1 individual*).mp. or (Dependent adj1 patient*).mp. or Frail*.mp. or (care* adj1 facilit*).mp. or (care* adj1 staff*).mp. or carer*.mp. or (care* adj1 setting*).mp. or (care* adj1 resident*).mp. or institutionali*.mp.
3	(questionnaire* or survey* or interview* or focus group* or view* or experienc* or opinion* or attitude* or perce* or prefer* or qualitative).tw. or exp Qualitative Research/
4	1 and 2 and 3
5	(child* not adult*).mp.
6	limit 5 to "all child (0 to 18 years)"
7	4 not 6
8	limit 7 to English language

Table 4.5: MEDLINE search strategy to identify relevant primary qualitative studies.

4.3.8 Quality assessment

There is no consensus in the scientific field as to whether qualitative studies should be critically appraised in qualitative evidence synthesis (Munthe-Kaas *et al.*, 2019). There are many researchers who suggested that because research paradigms in the qualitative field are based mainly on relativism, the concept of using a definitive methodological criteria to establish truth is in contrast with these paradigms, and therefore quality assessment should not be performed (Barusch *et al.*, 2011). On the other hand, other researchers believe that the critical appraisal is always done by the end readers and adopting a standardised tool will help the appraisal to be conducted and presented in a more systematic and transparent way (Lewin *et al.*, 2015). This is deemed especially true when qualitative evidence synthesis aims to inform the decision-making during the development of new policies and clinical interventions (Lewin *et al.*, 2015). This may explain why most of the published qualitative evidence synthesis about health and social care interventions have reported appraising the quality of their included studies (Dalton *et al.*, 2017).

Quality assessment of included studies' methods was carried out independently by two reviewers, (FB) and Dr Margaret Stewart (MS), using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (Critical Appraisal Skills Programme, 2018). The CASP is a checklist that consists of 10 questions. It is one of the most widely used critical appraisal tools in the qualitative evidence synthesis area (Noyes *et al.*, 2018a). In addition, this tool has been recommended to be used by less experienced reviewers because it is comparatively easier to understand and administer than other tools (Majid and Vanstone, 2018). In cases of disagreement, a decision was taken through discussion between the two reviewers and with one of the supervisors (RW) when necessary.

Quality assessment was performed to inform data synthesis and interpretation, and no study was excluded based on the findings of this assessment. This is mainly because the words limit used in journals can lead to not fully reporting all aspects of a study. Thus, it was considered that performing confidence assessment based on the findings of the quality assessment would be more appropriate than a straightforward exclusion of studies that potentially were just inadequately reported (Carroll and Booth, 2015). By conducting the confidence assessment (described in section 4.3.10) instead of excluding those studies, there was also a higher potential to generate conclusions that are more generalisable because by including more studies, there is a higher chance to represent a wider range of dependent adults from different settings with different causes of dependency (Carroll and Booth, 2015).

4.3.9 Data extraction and coding

Data extraction was done independently by two reviewers (FB & MS) using a pre-designed form (Appendix A). Extracted information included the characteristics of studies' populations, participants, settings and the studies' aims.

Qualitative data that were relevant to the review question were extracted and coded against the *a priori* framework by two independent reviewers (FB & MS). Qualitative data were extracted from results and discussion sections because many journals request authors to present their interpretation of the findings in the discussion section (Noyes *et al.*, 2018a). Extracted data were in the form of participants' verbatim quotations and interpretations reported by authors that are obviously supported by study data. Remaining evidence that was not captured by the *a priori* framework was extracted without being coded by the two independent reviewers (FB & MS) to be later thematically analysed.

4.3.10 Data synthesis

Data synthesis was done in three stages:

Stage 1: creating the new conceptual framework

Through the data extraction step, the names or definitions of the existing codes in the *a priori* framework were constantly revised to facilitate capturing data more accurately. This was done by continuously discussing the outcomes of the coding process between the two reviewers, which was also undertaken to identify and resolve any coding disagreements.

Data that were not captured by the *a priori* framework were analysed through undertaking an iterative thematic analysis of these data by the two independent reviewers (FB & MS). This thematic analysis started by familiarising with non-coded data through reading and rereading them, accompanied by recording initial ideas and comments. Then, open coding was performed to generate codes that are grounded in these data. A discussion between the two reviewers (FB & MS) about the new generated codes was undertaken to achieve a consensus regarding the names of these codes and their definitions. The newly generated codes and the revised codes in the *a priori* framework formed the new conceptual framework.

The new conceptual framework was created by two reviewers from different backgrounds, where FB is from a dental and academic background and MS is from a biomedical and administrative background. This was considered to be important because, epistemologically, this synthesis has adopted an interpretivist stance. This stance stresses on the notion that truth and knowledge are subjective, and are culturally and historically situated, based on people's experiences and their understanding of them. Researchers, therefore, can never be completely separate from their own values and beliefs, because these values and beliefs would inevitably influence the way in which they interpret and analyse data (Ryan, 2018). It has been suggested, therefore, that utilising different perspectives during the data analysis would generate findings that are more credible and more reasonable in representing the phenomenon under investigation (Barusch *et al.*, 2011).

Stage 2: creating the conceptual model

The second stage of data synthesis aimed to generate a new conceptual model that could explain oral health in dependent adults. This was done in two steps. First, the codes in the new framework were clustered and subsumed as “internal attributes” within higher and more abstract themes by combining codes that share commonalities. Second, these higher themes and their “internal attributes” were contextualised with reference to the data to understand their relationships.

Stage 3: assessing confidence in the evidence from the review findings

To assess the degree of confidence that could be placed on the findings from this review, the Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) approach was used. This approach allows making explicit, transparent and systematic decisions about the degree of confidence that can be placed for each review finding (Lewin *et al.*, 2018b). Confidence in this context means to what degree is a review finding a true representation of the phenomenon being investigated (Lewin *et al.*, 2018b). There are four components that were assessed to make an overall decision about the confidence: methodological limitations, coherence, adequacy of data and relevance (Lewin *et al.*, 2018b).

The methodological limitation component is about robustness of design and conduct of the primary qualitative studies that are contributing to the synthesis of a review’s findings (Munthe-Kaas *et al.*, 2018). The coherence component is about the degree that a review finding has a clear and cogent fit with the data from the primary qualitative studies (Colvin *et al.*, 2018). The adequacy of data component is about the richness and quantity of data that support a particular review finding (Glenton *et al.*, 2018). The relevance component is about the extent of applicability between the primary qualitative studies context and the context stated in the review research question (Noyes *et al.*, 2018b).

Each one of these components was assessed for every review finding by categorising concerns identified for each component into one of the following categories: no or very minor concerns, minor concerns, moderate concerns or serious concerns (Lewin *et al.*, 2018a). Based on the outcomes of the four components’ categorisation, an overall

CERQual assessment of confidence was then made for each review finding. The outcome of the overall CERQual assessment was one the following: high confidence, moderate confidence, low confidence or very low confidence (Lewin *et al.*, 2018a).

A limitation in the CERQual approach is, however, that it does not account for the effect of dissemination bias on the confidence. Booth *et al.* (2018) defined dissemination bias in qualitative research as “a systematic distortion of the phenomenon of interest due to selective dissemination of qualitative studies or the findings of qualitative studies”. While the exact extent of this type of bias in qualitative research is unknown, several studies have indicated that most probably it is similar to that in quantitative biomedical field (Petticrew *et al.*, 2008; Toews *et al.*, 2017). Nonetheless, because there is still a significant gap in the understanding of the effect of dissemination bias on the findings of qualitative evidence syntheses, dissemination bias was not included in the CERQual approach (Booth *et al.*, 2018).

4.4 Results

4.4.1 Results of literature searches

The search process in this review retrieved a total of 6126 studies. Electronic bibliographic database searches identified 4087 studies (1222 MEDLINE, 1598 Embase, 1160 CINAHL and 107 PsycINFO). In addition, 190 studies were found through searching grey literature sources (30 OpenGrey and 160 OATD). Furthermore, the manual search of citations and reference lists of the included studies identified 1849 studies (356 SCOPUS, 218 Web of Science and 1275 reference lists manual search).

After removal of duplicates, initial screening of the titles and abstracts was performed on 3875 studies. 3753 studies did not meet the predetermined inclusion criteria of this qualitative evidence synthesis and therefore were excluded. The full-text copies of the 122 potentially eligible studies were then retrieved and 95 studies were excluded after the full-text screening for three main reasons: not being about oral health or dependent adults, or qualitative data were not provided. A detailed list of excluded studies with the reasons of exclusion can be found in Appendix B. This left 27 studies that met the inclusion criteria and were included for data extraction and synthesis. The PRISMA flow diagram in Figure 4.2 summarises the retrieval, screening and selection processes. The main characteristics of the 27 studies included are illustrated in Table 4.6.

4.4.2 Methodological quality of the included studies

Using the CASP tool for evaluating quality, the majority of the 27 included studies were shown to have an acceptable level of methodological quality. Most of the methodological flaws were about the relationship between researcher and participants (question 6). This is because many of the included studies did not discuss the potential impact of this relationship on their findings. In addition, many studies had flaws in their recruitment strategy (question 4), because most of them have utilised inappropriate sampling strategies for qualitative research such as random or self-selection sampling techniques. Table 4.7 summarises the findings of the quality assessment of the included studies using the CASP tool.

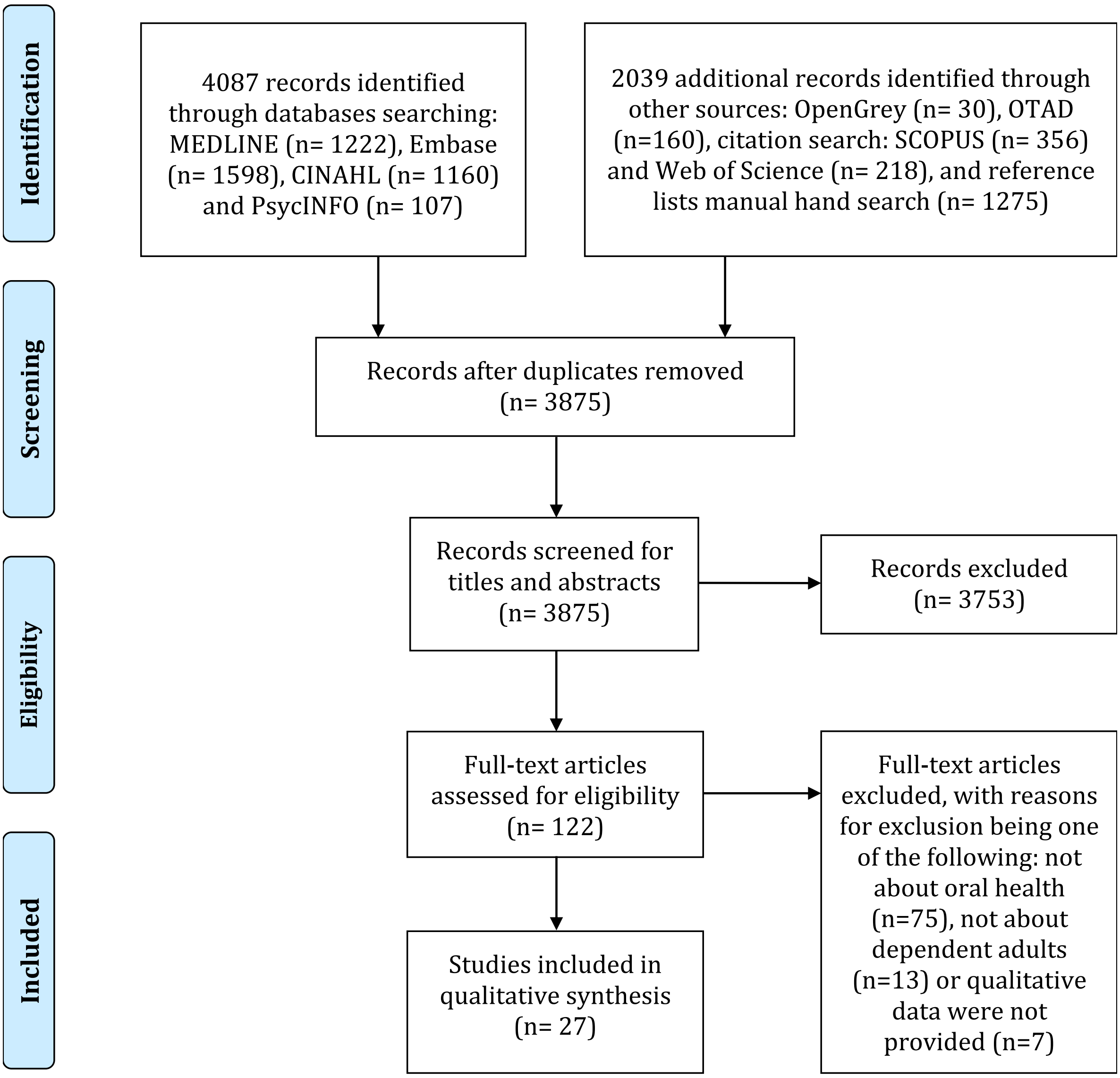

Figure 4.2: PRISMA flow diagram for retrieval, screening and selection processes in the qualitative evidence synthesis.

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
1	Weeks and Fiske (1994)	UK	Care home	22 caregivers of adults with physical-related dependency	"To explore the views of nursing staff with regard to the residents' oral care"	Semi-structured interviews
2	Fiske and Zhang (1999)	UK	Community	12 caregivers of adults with mental-related and age-related dependency	"To identify the roles of food in a day-centre for elderly, mentally ill people, so that dietary recommendations for optimal oral health are made within the overall philosophies of the day-centre"	Semi-structured interviews
3	MacEntee (1999)	Canada	Care homes	39 adults with age-related dependency and 70 caregivers	"To identify factors that influence oral health care in long term care facility within the context of the question: what impact does an oral health care program have on the residents of a long term care facility"	Semi-structured interviews
4	Cumella *et al.* (2000)	UK	Community & care homes	60 adults with mental-related dependency and their main caregivers	"To explore a group of adults with intellectual disability perceptions of teeth and contact with dentists to identify how oral care can be improved"	Semi-structured interviews

Study number	**Author (Year)**	**Country**	**Setting**	**Sample**	**Aim**	**Method**
5	Paulsson *et al.* (2002)	Sweden	Care homes	17 caregivers of adults with age-related dependency	"To develop a model for how nursing personnel view oral health in general and the oral health of the care receivers in particular, applying a health promotion perspective"	Semi-structured interviews
6	Paley *et al.* (2004)	Australia	Care homes	54 caregivers of adults with age-related dependency	"To determine manager and staff perceptions of oral health and dental service issues for residents in aged care facilities in the Perth Metropolitan Area, Western Australia"	Focus groups & semi-structured interviews
7	Hui (2008)	Canada	Care homes	6 adults with age-related dependency	"To explore the significance of oral health in the lives of Cantonese-speaking elderly Chinese immigrants in Vancouver, Canada"	Semi-structured interviews
8	Paley *et al.* (2009)	Australia	Care homes	21 adults with age-related dependency and 9 caregivers	"To explore oral health and dental service perceptions and attitudes for those in both high and low aged care facilities in Perth, Western Australia from the perspective of residents and their families"	Focus groups & semi-structured interviews

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
9	Persson *et al.* (2010)	Sweden	Care homes	10 adults with mental-related dependency	“To explore how persons with severe mental illness experience oral health problems and weigh the support they received in this regard from staff at community-based congregate housing during a controlled intervention programme”	Semi-structured interviews
10	Donnelly (2011)	Canada	Care homes	23 adults with age-related dependency	“To explore the relationships between oral health, body image and social interactions specific to institutionalized elders, and to develop through the inquiry a theoretical model that could accommodate the relationships”	Semi-structured interviews
11	Reis *et al.* (2011)	Brazil	Care home	10 caregivers of adults with age-related dependency	“To explore caregivers’ perceptions of oral health care and factors influencing their work in a public long-term care institution for the elderly in Goiania, Brazil”	Semi-structured interviews
12	Finkleman *et al.* (2012)	Canada	Care homes	61 adults with age-related dependency	“To explore how integration of dental service in long term care impacts oral health”	Semi-structured interviews

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
13	McKelvey (2012)	New Zealand	Community & care homes	13 adults with mental-related dependency	"To examine the use of oral health services by adults with intellectual disability"	Semi-structured interviews
14	Niesten *et al.* (2012)	Netherlands	Community & care homes	38 adults with age-related dependency	"To investigate how do natural teeth contribute to the quality of life of dentulous people who are elderly and frail and how does frailty influence the impact of having natural teeth on quality of life"	Semi-structured interviews
15	Unfer *et al.* (2012)	Brazil	Care homes	26 caregivers of adults with age-related dependency	"To describe how caregivers perceive the oral health status in the elderly they care for; the routines for oral hygiene in nursing homes; caregivers perceived barriers for quality oral care; the relationship between the caregivers' self-care and the care they provide to institutionalised elderly; and the caregivers competence and need for training in this area"	Semi-structured interviews

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
16	Yoon and Steele (2012)	Canada	Hospital & care homes	28 caregivers of dependent adults	"To explore perspectives regarding oral care held by nursing staff, speech–language pathologists and dental hygienists in long-term care institutions and to understand how their perspectives impact activities and processes involved in the delivery of oral care"	Focus groups
17	Lindqvist *et al.* (2013)	Sweden	Care homes	23 caregivers of adults with age-related dependency	"To explore what professionals with different responsibilities may consider as being important aspects of well-functioning daily oral care"	Semi-structured interviews
18	Niesten *et al.* (2013)	Netherlands	Community & care homes	51 adults with age-related dependency	"To investigate how frailty influences dental service-use and oral self-care by older people"	Semi-structured interviews
19	Tham and Hardy (2013)	Australia	Care homes	6 adults with age-related dependency and 21 caregivers	"To identify major issues in providing and accessing oral health care in Victorian rural residential aged care services from the perspectives of dentists, aged care staff and residents"	Focus groups & structured interviews

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
20	McKibbin *et al.* (2014)	USA	Community	25 adults with mental-related dependency	"To examine factors influencing service utilization among adults with severe mental illness"	Semi-structured interviews
21	Brocklehurst *et al.* (2015)	UK	Community	6 caregivers of adults with age-related dependency	"To establish a Priority Setting Partnerships to understand what aspects of oral health are considered important"	Focus group
22	De Visschere *et al.* (2015)	Belgium	Care homes	66 caregivers of adults with age-related dependency	"To report on barriers and enablers experienced by nurses when carrying out oral health care"	Focus groups & semi-structured interviews
23	Gilmour *et al.* (2016)	New Zealand	Community	5 adults with age-related dependency and 12 caregivers	"To explore the oral health experiences of both Māori with dementia and their whanau [family members]"	Semi-structured interviews
24	Mac Giolla Phadraig *et al.* (2016)	Ireland	Not reported	6 adults with mental-related dependency	"To identify priorities regarding oral health services for people with disabilities"	Focus group

Study number	Author (Year)	Country	Setting	Sample	Aim	Method
25	Hoang *et al.* (2018)	Australia	Care homes	20 caregivers of adults with age-related dependency	"To examine aged care staff's views on the implementation of training at their facilities; challenges that they faced in the provision of oral health care to residents and their training needs"	Semi-structured interviews
26	Stephenson *et al.* (2018)	New Zealand	Care homes	30 caregivers of adults with age-related dependency	"To obtain a deeper understanding of oral health knowledge and attitudes among staff caring for older people in long-term care facilities"	Semi-structured interviews
27	Villarosa *et al.* (2018)	Australia	Care homes	12 caregivers of adults with age-related dependency	"To look at the practices and perspectives of residential aged care facility care staff regarding the provision of oral health care"	Focus group

Table 4.6: Main characteristics of the 27 studies included in the qualitative evidence synthesis.

Study No.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Question 1	**Was there a clear statement of the aims of the research?**																										
	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 2	**Is a qualitative methodology appropriate?**																										
	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 3	**Was the research design appropriate to address the aims of the research?**																										
	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 4	**Was the recruitment strategy appropriate to the aims of the research?**																										
	✕	✕	○	○	○	○	○	○	○	○	○	✕	✕	○	○	✕	○	○	✕	○	○	○	✕	○	✕	✕	✕
Question 5	**Was the data collected in a way that addressed the research issue?**																										
	○	○	○	○	○	○	✕	○	○	○	○	○	○	○	✕	○	○	○	○	○	○	○	✕	✕	○	○	✕
Question 6	**Has the relationship between researcher and participants been adequately considered?**																										
	○	✕	○	✕	○	○	✕	✕	○	○	✕	✕	✕	○	✕	○	✕	○	✕	✕	○	✕	✕	○	○	✕	✕
Question 7	**Have ethical issues been taken into consideration?**																										
	○	✕	○	✕	○	○	○	○	○	○	✕	✕	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 8	**Was the data analysis sufficiently rigorous?**																										
	✕	✕	○	✕	○	○	○	○	○	○	○	✕	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 9	**Is there a clear statement of findings?**																										
	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Question 10	**Is the research valuable?**																										
	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

○ = Yes, ✕ = No

Table 4.7: Quality assessment of included studies using the CASP tool.

4.4.3 Emerging themes from the synthesis

Four major themes emerged from this qualitative evidence synthesis, which further the understanding of the phenomenon of oral health in dependent adults. These themes are oral health status, oral health impact, oral care and the value of oral health. Whilst qualitative studies usually present the concepts and findings that support each theme in the form of paragraph(s), the concepts that compose the themes of this qualitative evidence synthesis are presented below in the form of findings. This was mainly done to improve the readability because each finding is accompanied with a summary of the GRADE-CERQual confidence assessment outcomes (detailed assessment outcomes is presented in the CERQual evidence profile in Appendix C), in-text citation of studies supporting the finding and direct quotes from the original studies that support the finding. In the beginning of each theme and subtheme, a brief summary is provided to explain what this theme or subtheme is about.

4.4.4 Oral health status theme

This theme explains how oral health is defined and evaluated in dependent adults by them and their caregivers. It shows how oral health in dependent adults is defined according to and evaluated based on four main criteria (domains), which are intactness and cleanliness of oral structures, oral pain and discomfort, oral functions and noticeable oral health aspects. The definitions and explanations for each criterion are presented in a distinctive subtheme. In addition, examples of oral health problems that are related to these criteria are provided. Furthermore, potential causes of these problems are described.

Intactness and cleanliness of oral structures subtheme

Oral structures in the context of this synthesis include dentures, as well as anatomical oral structures (e.g. teeth and gingiva). Under this subtheme, the first finding describes how the intactness and cleanliness of oral structures is one of the criteria that are used by dependent adults and their caregivers to evaluate oral health. In addition, a detailed list of problems that are related to oral structures was provided in Findings 1.2 to 1.5. Furthermore, several potential causes of deterioration of oral structures were described in Findings 1.8 to 1.11. Finally, differences between natural teeth and dentures were discussed in Findings 1.6 and 1.7.

Finding 1.1: Intactness and cleanliness of anatomical oral structures (i.e. teeth, gingiva and mucosa) and dentures are criteria that are used to assess oral health in dependent adults.

CERQual assessment of confidence in finding 1.1: High confidence

Supporting studies 1.1: (Weeks and Fiske, 1994; MacEntee, 1999; Paulsson *et al.*, 2002; Paley *et al.*, 2004; Hui, 2008; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Unfer *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014; De Visschere *et al.*, 2015; Villarosa *et al.*, 2018)

Quote 1.1.a (caregiver): *"When mentioning that the [oral] health of the elderly is bad, the caregivers referred to gingivitis … and dirt: more is gingivitis, these things they all have, and dirt of the food*" (Unfer *et al.*, 2012)

Quote 1.1.b (dependent adult): *"[Dependent adults] tended to refer to … cavities, and missing teeth when evaluating their oral health"* (McKibbin *et al.*, 2014)

Finding 1.2: Problems with teeth in dependent adults include being missing, decayed, fractured and mobile.

CERQual assessment of confidence in finding 1.2: High confidence

Supporting studies 1.2: (Hui, 2008; Persson *et al.*, 2010; Donnelly, 2011; Reis *et al.*, 2011; McKelvey, 2012; Unfer *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014; De Visschere *et al.*, 2015; Gilmour *et al.*, 2016; Hoang *et al.*, 2018; Villarosa *et al.*, 2018)

Quote 1.2.a (dependent adult): *"[Dependent adults] acknowledged that they had multiple dental problems including multiple cavities or broken or missing teeth"* (McKibbin *et al.*, 2014)

Quote 1.2.b (caregiver): *"I think her teeth [dependent adult's teeth] will wear out as they loosen … I think eventually they won't be there. Because she has lost quite a few of her teeth, and they just more—or—less had to be taken out because they were falling out."* (McKelvey, 2012)

Finding 1.3: Gingival problems in dependent adults include inflammation, swelling and bleeding.

> **CERQual assessment of confidence in finding 1.3:** Moderate confidence due to minor concerns in coherence and adequacy, and moderate concerns in relevance
>
> **Supporting studies 1.3:** (Weeks and Fiske, 1994; MacEntee, 1999; Paley *et al.*, 2004; Hui, 2008; Donnelly, 2011; Finkleman *et al.*, 2012; Unfer *et al.*, 2012; Yoon and Steele, 2012; De Visschere *et al.*, 2015)
>
> **Quote 1.3.a** (dependent adult): *"Another participant [dependent adult] commented about a gum disease: I had gum swelling recently."* (Hui, 2008)
>
> **Quote 1.3.b** (caregiver): *"A high number of ... bleeding gums ... indicating a high treatment backlog were frequently mentioned [by caregivers]."* (De Visschere *et al.*, 2015)

Finding 1.4: Other oral-related problems in dependent adults include dryness, thrush, ulcers and altered taste sensation.

> **CERQual assessment of confidence in finding 1.4:** Moderate confidence due to minor concerns in methodological limitations and adequacy, and moderate concerns in relevance
>
> **Supporting studies 1.4:** (Paley *et al.*, 2004; Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; Yoon and Steele, 2012; Tham and Hardy, 2013; De Visschere *et al.*, 2015; Hoang *et al.*, 2018; Villarosa *et al.*, 2018)
>
> **Quote 1.4.a** (dependent adults): *"I don't feel very good about my teeth [or] my mouth; always having a terrible taste."* (Donnelly, 2011)
>
> **Quote 1.4.b** (caregivers): *"Common oral health problems reported were ulcers ... [and] thrush"* (Tham and Hardy, 2013)

Finding 1.5: Denture problems in dependent adults include being ill-fitted, broken, trapping food or causing mucosal ulcers.

CERQual assessment of confidence in finding 1.5: Moderate confidence due to minor concerns in methodological limitations, and moderate concerns in adequacy and relevance

Supporting studies 1.5: (Paley *et al.*, 2004; Persson *et al.*, 2010; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014; Gilmour *et al.*, 2016; Stephenson *et al.*, 2018; Villarosa *et al.*, 2018)

Quote 1.5.a (dependent adult): *"I know people who say: I don't eat this fruit because I can't have those little seeds underneath my dentures*." (Niesten *et al.*, 2012)

Quote 1.5.b (caregiver): *"Denture-related issues were a significant source of discomfort… Discomfort involved a loose fit … [and] food impaction"* (Finkleman *et al.*, 2012)

Quote 1.5.c (caregiver): *"Oral health also influenced … the burden of infections and ulcers (the latter generally from ill-fitting dentures)"* (Paley et al., 2004)

Finding 1.6: Dentures when compared to natural teeth are viewed to be less functional, having poorer appearance and not contributing to quality of life like natural teeth.

CERQual assessment of confidence in finding 1.6: Moderate confidence due to minor concerns in coherence, and moderate concerns in adequacy and relevance

Supporting studies 1.6: (Cumella *et al.*, 2000; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; McKibbin *et al.*, 2014)

Quote 1.6.a (dependent adult): *"Most people thought that natural teeth looked better than artificial teeth"* (Niesten et al., 2012)

Quote 1.6.b (dependent adult): *"I enjoy having preserved my teeth [. . .] because I have noticed that most people of my age have dentures, and even quite a few people who are much younger than I am."* (Niesten *et al.*, 2012)

Finding 1.7: Dependent adults prefer dentures over natural teeth only when they would like to maintain autonomy (because dentures are easier to maintain), as well as when their teeth deteriorate to a significant point.

> **CERQual assessment of confidence in finding 1.7:** Moderate confidence due to minor concerns in adequacy, and moderate concerns in coherence and relevance
>
> **Supporting studies 1.7:** (Paley *et al.*, 2004; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013)
>
> **Quote 1.7** (dependent adult)**:** *"… reactions [identified] to the thought of losing control … a preference for dentures rather than being dependent on others to maintain natural teeth."* (Niesten *et al.*, 2012)

Finding 1.8: Cleanliness of the mouth is a determinant of the anatomical oral structures' intactness.

> **CERQual assessment of confidence in finding 1.8:** Moderate confidence due to minor concerns in methodological limitations, coherence and adequacy, and moderate concerns in relevance
>
> **Supporting studies 1.8:** (Fiske and Zhang, 1999; Donnelly, 2011; Finkleman *et al.*, 2012; Yoon and Steele, 2012; McKibbin *et al.*, 2014; De Visschere *et al.*, 2015; Hoang *et al.*, 2018)
>
> **Quote 1.8.a** (caregiver): *"But with a mouth that's not being kept clean you get swollen or bleeding gums"* (De Visschere *et al.*, 2015)
>
> **Quote 1.8.b** (caregiver): *"… staff believed that poor oral hygiene played an equal part in causing decay"* (Fiske and Zhang, 1999)

Finding 1.9: Type of diet is a determinant of natural teeth intactness.

> **CERQual assessment of confidence in finding 1.9:** High confidence
>
> **Supporting studies 1.9:** (Weeks and Fiske, 1994; Fiske and Zhang, 1999; McKelvey, 2012; Niesten *et al.*, 2012; Niesten *et al.*, 2013)

Quote 1.9.a (dependent adult): *"You owe it to yourself to maintain a healthy mouth […] I live healthily, I hardly ever take sweets"* (Niesten *et al.*, 2013)

Quote 1.9.b (caregiver): *"… some staff realized sugar was an important aetiological factor in dental caries"* (Fiske and Zhang, 1999)

Finding 1.10: Some medications cause oral dryness, which deteriorates the intactness and cleanliness of natural teeth.

CERQual assessment of confidence in finding 1.10: Low confidence due to moderate concerns in relevance and adequacy, and serious concerns in coherence

Supporting studies 1.10: (Persson *et al.*, 2010; Finkleman *et al.*, 2012; Yoon and Steele, 2012; Tham and Hardy, 2013; McKibbin *et al.*, 2014)

Quote 1.10 (dependent adult): *"I have ugly spots – holes – in my front teeth. It was the medicine: the dry mouth started when I began taking that medicine. I brushed my teeth but it did not help."* (Persson *et al.*, 2010)

Oral pain and discomfort subtheme

The first finding under this subtheme describes how oral pain and discomfort are criteria that are used by dependent adults and their caregivers to evaluate oral health. The second finding describes potential causes of oral pain and discomfort.

Finding 1.11: Oral pain and discomfort are criteria that are used to assess oral health in dependent adults.

CERQual assessment of confidence in finding 1.11: High confidence

Supporting studies 1.11: (MacEntee, 1999; Cumella *et al.*, 2000; Paulsson *et al.*, 2002; Paley *et al.*, 2004; Hui, 2008; Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; McKibbin *et al.*, 2014; Brocklehurst *et al.*, 2015; Hoang *et al.*, 2018)

Quote 1.11.a (dependent adult): *"[Dependent adults] tended to refer to dental pain … when evaluating their oral health."* (McKibbin *et al.*, 2014)

Quote 1.11.b (caregiver): *"What we [caregivers] perceive is, they're not complaining of a toothache … Then we would say, for the moment, things are fine"* (MacEntee, 1999)

Finding 1.12: Oral pain and discomfort are consequences of deterioration in the intactness and cleanliness of oral structures.

CERQual assessment of confidence in finding 1.12: Moderate confidence due to minor concerns in coherence, and moderate concerns in adequacy and relevance

Supporting studies 1.12: (Fiske and Zhang, 1999; MacEntee, 1999; Paley *et al.*, 2004; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Niesten *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014)

Quote 1.12.a (dependent adult): *"In the morning it feels like there is acid in my mouth; some nurses do not know how to clean teeth properly"* (Finkleman *et al.*, 2012)

Quote 1.12.b (caregiver): *"[Caregivers believe] ill-fitting dentures and diseased teeth and soft tissues caused pain"* (Tham and Hardy, 2013)

Oral functions subtheme

The first finding under this subtheme describes the functions that are considered as a part of oral functions and how the ability to perform these functions is used by dependent adults and their caregivers as a criterion to evaluate oral health. The other findings describe the potential causes of oral dysfunction in dependent adults.

Finding 1.13: Oral functions (i.e. eating and speaking) are criteria that are used to assess oral health in dependent adults.

CERQual assessment of confidence in finding 1.13: Moderate confidence due to serious concerns in coherence and moderate concerns in relevance

Supporting studies 1.13: (MacEntee, 1999; Cumella *et al.*, 2000; Paulsson *et al.*, 2002; Paley *et al.*, 2004; Hui, 2008; Paley *et al.*, 2009; Persson *et al.*, 2010; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Niesten *et al.*, 2012; Yoon and Steele, 2012; Lindqvist *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014; Brocklehurst *et al.*, 2015; Gilmour *et al.*, 2016)

Quote 1.13.a (dependent adult): *"I can eat anything. So my mouth is O.K."* (Hui, 2008)

Quote 1.13.b (dependent adult): *"Q1: What aspects of oral health are important for you now? ... maintaining function were seen as very important"* (Brocklehurst *et al.*, 2015)

Finding 1.14: Oral dysfunction is a consequence of teeth loss and dentures deterioration.

CERQual assessment of confidence in finding 1.14: Moderate confidence due to moderate concerns in coherence and relevance

Supporting studies 1.14: (Fiske and Zhang, 1999; MacEntee, 1999; Cumella *et al.*, 2000; Paley *et al.*, 2004; Paley *et al.*, 2009; Persson *et al.*, 2010; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Yoon and Steele, 2012; Lindqvist *et al.*, 2013; Tham and Hardy, 2013; Brocklehurst *et al.*, 2015; Gilmour *et al.*, 2016; Mac Giolla Phadraig *et al.*, 2016; Stephenson *et al.*, 2018)

Quote 1.14.a (dependent adult): *"... without healthy teeth you couldn't chew anymore"* (Donnelly, 2011)

Quote 1.14.b (caregiver): *"All the interviewees [caregivers] considered it was important for elderly people to have teeth (whether natural or artificial) for ... the ability to chew well"* (Fiske and Zhang, 1999)

Finding 1.15: Oral pain and discomfort lead to eating problems.

CERQual assessment of confidence in finding 1.15: Low confidence due to minor concerns in methodological limitations, moderate concerns in coherence, and serious concerns in adequacy and relevance

Supporting studies 1.15: (Finkleman *et al.*, 2012; Yoon and Steele, 2012; Tham and Hardy, 2013; Stephenson *et al.*, 2018; Villarosa *et al.*, 2018)

Quote 1.15 (caregiver): *"If they've got painful gums ... then they won't eat, refuse to eat."* (Villarosa *et al.*, 2018)

Noticeable oral health aspects subtheme

The first two findings under this subtheme describe what noticeable oral health aspects mean in dependent adults. The last two findings describe potential causes of decline in the noticeable oral health aspects.

Finding 1.16: Oral health aspects that are noticeable by others (i.e. appearance and odour) are criteria that are used to assess oral health in dependent adults.

CERQual assessment of confidence in finding 1.16: High confidence

Supporting studies 1.16: (Weeks and Fiske, 1994; Cumella *et al.*, 2000; Paulsson *et al.*, 2002; Paley *et al.*, 2009; Donnelly, 2011; Finkleman *et al.*, 2012; Unfer *et al.*, 2012; Yoon and Steele, 2012; McKibbin *et al.*, 2014; De Visschere *et al.*, 2015; Gilmour *et al.*, 2016; Mac Giolla Phadraig *et al.*, 2016; Villarosa *et al.*, 2018)

Quote 1.16.a (dependent adult): *"The respondents ... relied on appearance ... to judge the condition of their teeth."* (Cumella *et al.*, 2000)

Quote 1.16.b (caregiver): *"To frontline nursing staff, oral health appears to mean having fresh smelling breath"* (Yoon and Steele, 2012)

Finding 1.17: The meanings of good oral appearance that dependent adults would like to have are: i) looking well-groomed and cared for, ii) having well aligned and white teeth, iii) having appearance that is natural and compatible with their age.

CERQual assessment of confidence in finding 1.17: Moderate confidence due to moderate concerns in adequacy and relevance

Supporting studies 1.17: (Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Niesten *et al.*, 2013)

Quote 1.17.a (dependent adult): *"For most participants, good appearance equalled looking neat and well cared for"* (Niesten *et al.*, 2012)

Quote 1.17.b (dependent adult): *"I have always had these yellow teeth, but I wish they could be whiter … because whiter teeth are nicer. It looks as though I don't take care of them"* (Donnelly, 2011)

Quote 1.17.c (dependent adult): *"If you are 75 and you have a beautiful set of teeth, well that's a strange sight isn't it? I think that your face is allowed to show that you are not 20 or 30 anymore, no matter if it is about your teeth or your eyes or your skin."* (Niesten *et al.*, 2012)

Finding 1.18: Problems in the intactness of natural teeth and dentures are determinant for creating poor oral appearance.

CERQual assessment of confidence in finding 1.18: Moderate confidence due to minor concerns in coherence and adequacy, and moderate concerns in relevance

Supporting studies 1.18: (Fiske and Zhang, 1999; Cumella *et al.*, 2000; Paulsson *et al.*, 2002; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Gilmour *et al.*, 2016; Mac Giolla Phadraig *et al.*, 2016)

Quote 1.18.a (dependent adult): *"[My decayed teeth] makes me look uglier"* (Cumella *et al.*, 2000)

Quote 1.18.b (caregiver): *"Without teeth you look funny"* (Paulsson *et al.*, 2002)

Finding 1.19: Deterioration in oral cleanliness is determinant for creating noticeable bad oral odour.

CERQual assessment of confidence in finding 1.19: Low confidence due to serious concerns in adequacy and relevance

Supporting study 1.19: (Donnelly, 2011)

Quote 1.19 (dependent adult): *"Those who felt that they had a clean mouth had little concern about bad breath, but they would want something done if it did occur, as Fran explained sternly: Well I'd get rid of it first off. If I found I had [bad breath] I'd get rid of it, I really would. I can still think that way and do it … you have to keep yourself clean."* (Donnelly, 2011)

4.4.5 Oral health impact theme

This theme covers how the decline and deterioration in oral health status impacts on three aspects of dependent adults' life, which are presented under three different subthemes: quality of life, general health and behaviours.

Quality of life subtheme

Findings 2.1 to 2.10 in this subtheme describe several means by which oral health decline impacts directly or indirectly on dependent adults' quality of life.

Finding 2.1: Intactness and cleanliness of oral structures alter the dependent adults' feeling about their wholeness and achievements, which impact on how dependent adults evaluate themselves (self-worth). Self-worth contributes to the sense of self-esteem, dignity and pride and subsequently overall quality of life.

> **CERQual assessment of confidence in finding 2.1:** Low confidence due to moderate concerns about relevance and adequacy, and serious concerns about coherence
>
> **Supporting studies 2.1:** (Cumella *et al.*, 2000; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014)
>
> **Quote 2.1** (dependent adult): *"I don't want to lose my teeth ... It's pride – I don't want to lose my pride... I'd go mad. Cause if they all go bad you gotta have them all out... I like me own teeth"* (Cumella *et al.*, 2000)

Finding 2.2: Ability to perform oral functions affects dependent adults' self-worth, which subsequently contributes to their quality of life.

> **CERQual assessment of confidence in finding 2.2:** Low confidence due to moderate concerns about relevance and adequacy, and serious concerns about coherence
>
> **Supporting studies 2.2:** (Fiske and Zhang, 1999; Hui, 2008; Donnelly, 2011; Niesten *et al.*, 2012; McKibbin *et al.*, 2014)
>
> **Quote 2.2** (dependent adult): *"I don't eat apples no more. They just make my teeth pop ... It's horrible. It's frustrating ... having to learn how to do everything all over*

again, talk, eat, drink, breathe because if you get too much air behind that plate it will pop that plate out … then you're trying to catch your teeth." (McKibbin *et al.*, 2014)

Finding 2.3: Oral health problems that are noticeable by others affect dependent adults' self-worth, which subsequently contributes to their quality of life.

CERQual assessment of confidence in finding 2.3: Moderate confidence due to moderate concerns about relevance and adequacy

Supporting studies 2.3: (Weeks and Fiske, 1994; Fiske and Zhang, 1999; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; McKibbin *et al.*, 2014)

Quote 2.3.a (dependent adult): *"I had had very attractive teeth before … something I was proud of."* (Persson *et al.*, 2010)

Quote 2.3.b (caregiver): *"… oral health appears to mean having fresh smelling breath so that patients have high self-esteem"* (Yoon and Steele, 2012)

Finding 2.4: Performing self-daily oral care sustains the dependent adults' sense of being the same person as before dependency and the sense of autonomy, which results in a higher self-worth and subsequently better quality of life.

CERQual assessment of confidence in finding 2.4: Moderate confidence due to minor concerns about coherence, and moderate concerns about relevance and adequacy

Supporting studies 2.4: (Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013)

Quote 2.4.a (dependent adult): *"I just wanted to feel normal again. When you do your daily routines, combing your hair, brushing your teeth, just like you always do, it feels as if you're not that ill."* (Niesten *et al.*, 2013)

Quote 2.4.b (dependent adult): *"When I asked Kate to tell me what it might be like not to be able to take care of her teeth she replied, It's gonna be hell because I'm*

> *very independent and to take everything away from me, it's gonna be hard to handle."* (Donnelly, 2011)

Finding 2.5: Ability to perform oral functions during social interaction affects how dependent adults feel they are evaluated by others (social worth), which subsequently affects their quality of life.

> **CERQual assessment of confidence in finding 2.5:** Very low confidence due to serious concerns about coherence, adequacy and relevance
>
> **Supporting studies 2.5:** (Donnelly, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012)
>
> **Quote 2.5.a** (dependent adult): *"... like in restaurants, I would hate it if I would have to skip menu's or dishes because of fear of dentures falling out or food sticking to those fake teeth or whatever... It would take away the joy of eating out."* (Niesten *et al.*, 2012)
>
> **Quote 2.5.b** (dependent adult): *"I don't have teeth. I know I am talking pretty much [normally], but it is not easy to talk without teeth. Your tongue is trying to make-up for the fact that there is a space there and everything doesn't come out for you the way you intended. So yes, I am troubled when people come [to see me]"* (Donnelly, 2011)

Finding 2.6: Oral health problems that are noticeable by others affect dependent adults' social worth, which subsequently affects their quality of life.

> **CERQual assessment of confidence in finding 2.6:** Moderate confidence due to minor concerns about relevance, and moderate concerns about adequacy, and serious concerns about coherence
>
> **Supporting studies 2.6:** (Weeks and Fiske, 1994; Fiske and Zhang, 1999; Cumella *et al.*, 2000; Paley *et al.*, 2004; Persson *et al.*, 2010; Donnelly, 2011; Niesten *et al.*, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; McKibbin *et al.*, 2014; Mac Giolla Phadraig *et al.*, 2016)
>
> **Quote 2.6** (dependent adult): *"Once we were at a family party and there was this young guy there. He was very young but he just sat there with his mouth open and*

gaped at my teeth. They were all black, and he looked at them all the time – just sat and stared at them. And so I got nervous … I was too nervous. Can you imagine? He was just a little guy and he saw my bad teeth. It was terrible!" (Persson *et al.*, 2010)

Finding 2.7: Performing daily oral care by caregivers for the dependent adults sustains their sense of being worthy and well-cared for, which results in a perceived higher social worth and subsequently better quality of life.

CERQual assessment of confidence in finding 2.7: Very low confidence due to serious concerns about coherence, adequacy and relevance

Supporting study 2.7: (Niesten *et al.*, 2013)

Quote 2.7.a (dependent adult): *"I wish to be cared for, I don't won't to lie here as a pile of old dirt, that goes for the mouth, for everything."* (Niesten *et al.*, 2013)

Quote 2.7.b (dependent adult): *"If a nurse talks to me and brushes my teeth and then she says, well that's nice and fresh like this, by saying so she lets me know that I still count as a human being."* (Niesten *et al.*, 2013)

Finding 2.8: Dependent adults who are worrying about a reduction in their social worth due to oral health problems, avoid certain oral functions during social interaction or completely avoid social interaction with others.

CERQual assessment of confidence in finding 2.8: High confidence

Supporting studies 2.8: (Weeks and Fiske, 1994; Cumella *et al.*, 2000; Paley *et al.*, 2004; Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; McKibbin *et al.*, 2014)

Quote 2.8.a (dependent adult): *"I would not like to smile at someone if my teeth would look bad."* (Niesten *et al.*, 2012)

Quote 2.8.b (dependent adult): *"Bonnie said that if she didn't have her dentures in her mouth, that she would never leave her room. Meryl said she wouldn't smile, and Tina would avoid people all together because she would be terrified of walking out into a group of people and having bad breath."* (Donnelly, 2011)

Finding 2.9: Oral pain and discomfort directly impacts on dependent adults' quality of life.

> **CERQual assessment of confidence in finding 2.9:** Low confidence due to moderate concerns about coherence and adequacy, and serious concerns about relevance
>
> **Supporting studies 2.9:** (Donnelly, 2011; Niesten *et al.*, 2012)
>
> **Quote 2.9** (dependent adult): *"Absence of pain and irritation was crucial to good ... [quality of life] for people across all frailty categories."* (Niesten *et al.*, 2012)

Finding 2.10: Ability to eat affects quality of life of dependent adults through the pleasure of eating food.

> **CERQual assessment of confidence in finding 2.10:** High confidence
>
> **Supporting studies 2.10:** (Fiske and Zhang, 1999; Hui, 2008; Paley *et al.*, 2009; Donnelly, 2011; Niesten *et al.*, 2012)
>
> **Quote 2.10** (dependent adult): *"However hopeless my body's condition is, I wish to eat properly. Otherwise my diet would be down to porridge. That would be horrible."* (Niesten *et al.*, 2012)

General health subtheme

Findings 2.11 to 2.14 in this subtheme describe several means by which deterioration in oral health status impacts on dependent adults' general health and mortality.

Finding 2.11: It is perceived that oral health status of dependent adults affects their general health.

> **CERQual assessment of confidence in finding 2.11:** High confidence
>
> **Supporting studies 2.11:** (Fiske and Zhang, 1999; MacEntee, 1999; Paulsson *et al.*, 2002; Paley *et al.*, 2004; Paley *et al.*, 2009; Donnelly, 2011; Reis *et al.*, 2011; Yoon and Steele, 2012; Lindqvist *et al.*, 2013; Niesten *et al.*, 2013; Tham and Hardy, 2013; Villarosa *et al.*, 2018)

> **Quote 2.11** (caregiver): *"If you have bad oral health I think it might have an influence on your general health"* (Paulsson *et al.*, 2002)

Finding 2.12: Eating ability impacts on the nutritional status and subsequently general health of dependent adults.

> **CERQual assessment of confidence in finding 2.12:** Moderate confidence due to minor concerns about coherence, and moderate concerns about adequacy and relevance
>
> **Supporting studies 2.12:** (Fiske and Zhang, 1999; MacEntee, 1999; Paulsson *et al.*, 2002; Paley *et al.*, 2004; Paley *et al.*, 2009; Donnelly, 2011; Reis *et al.*, 2011; Yoon and Steele, 2012; Lindqvist *et al.*, 2013; Tham and Hardy, 2013; Villarosa *et al.*, 2018)
>
> **Quote 2.12.a** (caregiver): *"If your oral health is not good, it will have consequences for the whole body and also for … nutrition."* (Paulsson *et al.*, 2002)
>
> **Quote 2.12.b** (dependent adult): *"… without healthy teeth you couldn't chew anymore and that would cause you intestinal problems."* (Donnelly, 2011)

Finding 2.13: Poor cleanliness of oral structures is linked to aspiration pneumonia incidences.

> **CERQual assessment of confidence in finding 2.13:** Low confidence due to minor concerns about methodological limitations, and moderate concerns about adequacy, and serious concerns about coherence and relevance
>
> **Supporting studies 2.13:** (Yoon and Steele, 2012; Lindqvist *et al.*, 2013)
>
> **Quote 2.13**(caregiver): *"[Caregivers are aware] that the presence of pathogenic bacteria in oropharyngeal secretions is linked to the risk of aspiration pneumonia, especially in patients with dysphagia"* (Yoon and Steele, 2012)

Finding 2.14: Declined general health due to oral health deterioration could cause death.

CERQual assessment of confidence in finding 2.14: Moderate confidence due to minor concerns about methodological limitations, and moderate concerns about adequacy, and serious concerns about relevance

Supporting studies 2.14: (Reis *et al.*, 2011; Lindqvist *et al.*, 2013; Stephenson *et al.*, 2018)

Quote 2.14 (caregiver): *"On the other hand, edentulousness and traumatic injuries caused by inappropriate dentures were associated with food restriction and appetite loss ... Caregivers related overall feeding difficulties and general organic depletion to physical weakness, immobility and increased risk of death."* (Reis *et al.*, 2011)

Behaviours subtheme

Finding 2.15: Oral pain and discomfort affect dependent adults' behaviours and ability to cooperate.

CERQual assessment of confidence in finding 2.15: Moderate confidence due to moderate concerns about relevance, and serious concerns about adequacy

Supporting studies 2.15: (Paley *et al.*, 2004; McKelvey, 2012; Yoon and Steele, 2012; Tham and Hardy, 2013)

Quote 2.15 (caregiver): *"For example, ill-fitting dentures and diseased teeth and soft tissues caused pain ... which impacted adversely on ... mood and ability to cooperate."* (Tham and Hardy, 2013)

4.4.6 Oral care theme

This theme covers the actions that are taken by/for a dependent adult to prevent oral health problems and their impacts, or to restore oral health status after deterioration. These actions are described and discussed under two subthemes, namely daily oral care and professional dental care.

Daily oral care subtheme

Daily oral care in the context of this subtheme means regular oral hygiene activities that are undertaken by/for dependent adults such as teeth brushing and dental flossing. Findings 3.1 to 3.4 under this subtheme describe how oral health status could motivate or hinder daily oral care to be undertaken by/for dependent adults.

Finding 3.1: Maintaining the intactness and cleanliness of oral structures initiates the desire for daily oral care to be undertaken by/for dependent adults.

> **CERQual assessment of confidence in finding 3.1:** Moderate confidence due to minor concerns about relevance, and serious concerns about coherence
>
> **Supporting studies 3.1:** (Weeks and Fiske, 1994; Fiske and Zhang, 1999; Cumella *et al.*, 2000; Paulsson *et al.*, 2002; Hui, 2008; Paley *et al.*, 2009; Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Niesten *et al.*, 2012; Niesten *et al.*, 2013; Tham and Hardy, 2013; McKibbin *et al.*, 2014; Brocklehurst *et al.*, 2015; De Visschere *et al.*, 2015; Gilmour *et al.*, 2016; Hoang *et al.*, 2018)
>
> **Quote 3.1.a** (dependent adult): *"You owe it to yourself to maintain a healthy mouth … I brush my teeth every night."* (Niesten *et al.*, 2013)
>
> **Quote 3.1.b** (caregiver): *"It is important that the care receivers have a good oral status and oral health. You have to take care of their teeth in the same way as you do your own."* (Paulsson *et al.*, 2002)

Finding 3.2: Prevention of oral pain and discomfort initiates the desire for daily oral care to be undertaken by/for dependent adults.

> **CERQual assessment of confidence in finding 3.2:** Moderate confidence due to moderate concerns about adequacy, and serious concerns about relevance
>
> **Supporting studies 3.2:** (Finkleman *et al.*, 2012; Yoon and Steele, 2012; Lindqvist *et al.*, 2013; Niesten *et al.*, 2013)
>
> **Quote 3.2** (caregiver): *"[Caregivers] also expressed compassion and empathised with patients' discomfort when oral care appeared to be lacking; this motivated them to carry through with getting the gunk off despite their feelings of repulsion"* (Yoon and Steele, 2012)

Finding 3.3: Prevention of noticeable oral health problems initiates the desire for daily oral care to be undertaken by/for dependent adults.

> **CERQual assessment of confidence in finding 3.3:** Moderate confidence due to minor concerns about coherence and adequacy, and moderate concerns about relevance
>
> **Supporting studies 3.3:** (Weeks and Fiske, 1994; Donnelly, 2011; Yoon and Steele, 2012; Niesten *et al.*, 2013; Gilmour *et al.*, 2016)
>
> **Quote 3.3.a** (dependent adult): *"For most participants the perceived benefits of tooth brushing (mainly, having fresh breath and feeling clean and well-groomed) outweighed the negative consequences of having to make the effort, or remind a nurse to do it."* (Niesten *et al.*, 2013)
>
> **Quote 3.3.b** (caregiver): *"[Undertaking daily oral care] just to give them the security that when people come near them and speak to them that at least what comes out of their mouth smells nice."* (Weeks and Fiske, 1994)

Finding 3.4: Deteriorated oral structures may act as a barrier preventing daily oral care to be performed by caregivers.

> **CERQual assessment of confidence in finding 3.4:** Very low confidence due to minor concerns about methodological limitations and serious concerns about coherence, adequacy and relevance
>
> **Supporting studies 3.4:** (Yoon and Steele, 2012; Tham and Hardy, 2013; De Visschere *et al.*, 2015; Hoang *et al.*, 2018)
>
> **Quote 3.4** (caregiver): *"An unhealthy mouth is not attractive and is off-putting in terms of being brushed"* (De Visschere *et al.*, 2015)

Professional dental care subtheme

Professional dental care in the context of this subtheme is dental treatment and care that are provided by dental professionals such as dentists and hygienists. Findings 3.5 to 3.8 under this subtheme describe how oral health status could motivate dependent adults or their caregivers to seek professional dental care.

Finding 3.5: Deterioration in oral structures' intactness initiates the desire to seek professional dental care to restore them.

CERQual assessment of confidence in finding 3.5: Moderate confidence due to moderate concerns about coherence and relevance

Supporting studies 3.5: (Fiske and Zhang, 1999; MacEntee, 1999; Cumella *et al.*, 2000; Hui, 2008; Persson *et al.*, 2010; Donnelly, 2011; Reis *et al.*, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Unfer *et al.*, 2012; Yoon and Steele, 2012; Tham and Hardy, 2013; Brocklehurst *et al.*, 2015; De Visschere *et al.*, 2015; Mac Giolla Phadraig *et al.*, 2016)

Quote 3.5 (dependent adult): *"If it's [tooth] broke fix it, if it ain't broke then don't fix it"* (Donnelly, 2011)

Finding 3.6: Oral pain and discomfort initiate the desire to seek professional dental care for relief.

CERQual assessment of confidence in finding 3.6: Moderate confidence due to minor concerns about adequacy, and moderate concerns about coherence and relevance

Supporting studies 3.6: (Hui, 2008; Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; McKelvey, 2012; Yoon and Steele, 2012; Niesten *et al.*, 2013; McKibbin *et al.*, 2014; Mac Giolla Phadraig *et al.*, 2016)

Quote 3.6.a (dependent adult): *"I wouldn't [see a dentist], not unless I would have serious toothache"* (Niesten et al., 2013)

Quote 3.6.b (dependent adult): *"I haven't really looked yet, [for a dentist in the community] cause I don't have a tooth ache or nothing."* (McKibbin *et al.*, 2014)

Finding 3.7: Oral dysfunctions initiate the desire to seek professional dental care for oral functions' rehabilitation.

CERQual assessment of confidence in finding 3.7: Low confidence due to moderate concerns about adequacy and relevance, and serious concerns about coherence

Supporting studies 3.7: (Donnelly, 2011; Reis *et al.*, 2011; Yoon and Steele, 2012; Mac Giolla Phadraig *et al.*, 2016)

Quote 3.7.a (dependent adult): *"Harry was unable to chew some foods with his broken teeth, and was considering the possibility of new dentures because, it would be nice to eat good food again. It would be nice to eat salads."* (Donnelly, 2011)

Quote 3.7.b (dependent adult): *"Participants clearly valued dental treatment as they saw it as a means of ... rehabilitation of function when teeth were lost."* (Mac Giolla Phadraig *et al.*, 2016)

Finding 3.8: Noticeable oral health problems initiate the desire to seek professional dental care to be fixed.

CERQual assessment of confidence in finding 3.8: Moderate confidence due to minor concerns about adequacy, and moderate concerns about relevance, and serious concerns about coherence

Supporting studies 3.8: (Persson *et al.*, 2010; Donnelly, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Mac Giolla Phadraig *et al.*, 2016)

Quote 3.8.a (dependent adult): *"How can [dental treatment] make a positive change in your life? ... Because you might have two or three [teeth] missing and you could go into a pub in town and the publican would think that you are a druggy or something"* (Mac Giolla Phadraig *et al.*, 2016)

Quote 3.8.b (dependent adult): *"However, once she started feeling better the health of her mouth was once again a priority, so much so that she even wanted her teeth whitened because the color also bothered her."* (Donnelly, 2011)

4.4.7 The value of oral health theme

The value of oral health in the context of this synthesis means how significant and important oral health is to dependent adults. This theme presents the factors that influence and change the value given to oral health by dependent adults. In addition, it describes the effect of the value on the other components of oral health (i.e. oral health status, oral impact and oral care) that were previously described in this synthesis.

Oral health value factors subtheme

Findings 4.1 to 4.9 in this subtheme describe the factors that influence and change the value placed by dependent adults on oral health.

Finding 4.1: Deterioration in general health reduces the value given to oral health by dependent adults.

> **CERQual assessment of confidence in finding 4.1:** Moderate confidence due to minor concerns about coherence and adequacy, and serious concerns about relevance
>
> **Supporting studies 4.1:** (Donnelly, 2011; Finkleman *et al.*, 2012; Niesten *et al.*, 2012; Lindqvist *et al.*, 2013; Niesten *et al.*, 2013)
>
> **Quote 4.1** (dependent adult): *"I am still relatively young now, but when I would be 85 or 90, I expect I would have a different view, depending on my general health. If my health would not further deteriorate, I would still think the same about my mouth, but I expect that I would care less if I would be demented or have other ailments that affect my life and that I cannot control. It really depends on which diseases I would have and how bad they would be."* (Niesten *et al.*, 2012)

Finding 4.2: Dependent adults prefer to focus their limited energy on serious general health conditions rather than on oral health, which could result in a reduction in the value of oral health.

> **CERQual assessment of confidence in finding 4.2:** Low confidence due to moderate concerns about coherence, and serious concerns about adequacy and relevance
>
> **Supporting studies 4.2:** (Niesten *et al.*, 2012; Niesten *et al.*, 2013)
>
> **Quote 4.2.a** (dependent adult): *"I don't see a dentist anymore. I don't feel like it. I rather preserve my energy for other things."* (Niesten *et al.*, 2013)
>
> **Quote 4.2.b** (dependent adult): *"Throughout the years, you don't know if your teeth are still important to you or not ... So many things play a role, like with my health in general. I can hardly walk anymore, I had to move to this home, so many*

things changed … I suppose it made me less concerned about my teeth." (Niesten *et al.*, 2012)

Finding 4.3: Believing that deterioration in oral health is an inevitable consequence of advancement in age or deterioration in general health reduces the value given to oral health by dependent adults.

CERQual assessment of confidence in finding 4.3: Low confidence due to moderate concerns about coherence and adequacy, and serious concerns about relevance

Supporting studies 4.3: (Fiske and Zhang, 1999; Hui, 2008; Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013)

Quote 4.3 (dependent adult): *"It is easy for me to accept that my teeth are getting worse. I don't really mind. It is something you can't change anyway … Everything gets worse with age"* (Niesten *et al.*, 2012)

Finding 4.4: Anticipating death in the near future reduces the value given to oral health by dependent adults.

CERQual assessment of confidence in finding 4.4: Very low confidence due to serious concerns about coherence, adequacy and relevance

Supporting studies 4.4: (Paley *et al.*, 2004; Donnelly, 2011; Niesten *et al.*, 2013)

Quote 4.4 (dependent adult): *"There was one period when I heard that I might die so I was very worried and didn't really know about that cause. I didn't know why, I didn't realize I was so ill … I wasn't too worried about my teeth"* (Donnelly, 2011)

Finding 4.5: Some dependent adults with deterioration in their general health place more value on oral health to remain the same as before health decline by keeping the same level of oral health.

CERQual assessment of confidence in finding 4.5: Low confidence due to serious concerns about adequacy and relevance

Supporting studies 4.5: (Niesten *et al.*, 2012; Niesten *et al.*, 2013)

> **Quote 4.5** (dependent adult): *"Having your own teeth, that means: a bit of self-preservation, you feel better about yourself. It means preservation of that small part of your body, while the rest is collapsing."* (Niesten *et al.*, 2012)

Finding 4.6: Deterioration in quality of life reduces the value given to oral health by dependent adults.

> **CERQual assessment of confidence in finding 4.6:** Low confidence due to minor concerns about coherence, and serious concerns about adequacy and relevance
>
> **Supporting studies 4.6:** (Donnelly, 2011; Niesten *et al.*, 2013)
>
> **Quote 4.6** (dependent adult): *"My teeth don't interest me. Because I am depressed."* (Niesten *et al.*, 2013)

Finding 4.7: Inability to perform or receive daily oral care and unavailability of access to professional dental care reduces the value given to oral health by dependent adults.

> **CERQual assessment of confidence in finding 4.7:** Low confidence due to moderate concerns about coherence, and serious concerns about adequacy and relevance
>
> **Supporting studies 4.7:** (MacEntee, 1999; Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013)
>
> **Quote 4.7.a** (dependent adult): *"I can't get them [teeth] 100% clean, not even with an electric toothbrush ... It is too hard to reach them ... I've tried, but it didn't work, and now it doesn't bother me anymore ... I don't mind losing my teeth."* (Niesten *et al.*, 2013)
>
> **Quote 4.7.b** (dependent adult): *"The residents accepted poor oral health ... because they were resigned to their condition through ... ignorance of the oral health services available."* (MacEntee, 1999)

Finding 4.8: Oral health of dependent adults' peers influences what they consider as optimal oral health and subsequently affects the value they place on oral health.

CERQual assessment of confidence in finding 4.8: Low confidence due to moderate concerns about coherence, and serious concerns about adequacy and relevance

Supporting studies 4.8: (Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013)

Quote 4.8.a (dependent adult): *"Minor imperfections, like skewed or stained or yellow teeth, did not bother them [dependent adults] enough to undertake action, mostly because they set their standards based on what they saw around them in their peer group"* (Niesten *et al.*, 2012)

Quote 4.8.b (dependent adult): *"When I asked Ed how he would feel if he was unable to wear his upper denture in public, he was unconcerned because he had seen people in the dining room eating without their dentures and believed that as a rule, people without an upper denture, they just keep on going."* (Donnelly, 2011)

Finding 4.9: Original beliefs and attitudes towards oral health influence the value given to oral health by dependent adults.

CERQual assessment of confidence in finding 4.9: Low confidence due to minor concerns about coherence, and serious concerns about adequacy and relevance

Supporting studies 4.9: (Donnelly, 2011; Niesten *et al.*, 2013)

Quote 4.9 (dependent adult): *"Janice, for example, had gone to the dentist regularly and did so annually. When I ask her to tell me if she had noticed any change in her teeth since she moved to the facility, she stated: they've gotten five years older. When I asked her about any change in their importance she replied sternly: What do you mean by importance? They are always important."* (Donnelly, 2011)

Oral health value effect subtheme

Findings 4.10 to 4.15 in this subtheme describe how a reduction in the value placed by dependent adults on oral health affect the other components in the oral health conceptual model (i.e. oral health status, oral health impact and oral care).

Finding 4.10: The amount of value placed by dependent adults on oral health affects how they evaluate their oral health (i.e. which criteria are used to define and evaluate their oral health).

> **CERQual assessment of confidence in finding 4.10:** High confidence
>
> **Supporting studies 4.10:** (Hui, 2008; Donnelly, 2011; Niesten *et al.*, 2013; McKibbin *et al.*, 2014)
>
> **Quote 4.10** (dependent adult): *"I know that I have some missing teeth and possibly some cavities. But I have no problems with my teeth and gums. And I can eat anything. So my mouth is O.K."* (Hui, 2008)

Finding 4.11: Oral structures lose their importance and value for dependent adults before the other three domains of oral health (i.e. pain, functions and noticeability).

> **CERQual assessment of confidence in finding 4.11:** Low confidence due to moderate concerns about adequacy, and serious concerns about coherence and relevance
>
> **Supporting studies 4.11:** (Donnelly, 2011; Niesten *et al.*, 2012; Gilmour *et al.*, 2016)
>
> **Quote 4.11** (dependent adult): *"… others said they would not bother about problem teeth if they were not painful or visible"* (Donnelly, 2011)

Finding 4.12: Oral pain and discomfort is the last domain of oral health that lose its importance and value in dependent adults.

> **CERQual assessment of confidence in finding 4.12:** Moderate confidence due to minor concerns about coherence, and moderate concerns about adequacy and relevance
>
> **Supporting studies 4.12:** (Hui, 2008; Donnelly, 2011; Niesten *et al.*, 2013; McKibbin *et al.*, 2014)
>
> **Quote 4.12.a** (dependent adult): *"I wouldn't [see a dentist], not unless I would have serious toothache. Life won't last that long anymore when you're so old as I am"* (Niesten *et al.*, 2013)

Quote 4.12.b (dependent adult): *"I just brush and rinse my mouth ... that's it! As far as my mouth is concerned, I adopt the just let-it-be attitude. If there is no toothache, I don't usually visit the dentist."* (Hui, 2008)

Finding 4.13: Noticeable oral health aspects lose their importance and value for dependent adults before oral functions.

CERQual assessment of confidence in finding 4.13: Low confidence due to serious concerns about adequacy and relevance

Supporting studies 4.13: (Donnelly, 2011; Niesten *et al.*, 2012)

Quote 4.13 (dependent adult): *"I think that the dental thing deserves a lot of priority, not cosmetically, but so that people can eat ... and that kind of stuff."* (Donnelly, 2011)

Finding 4.14: The amount of value placed by dependent adults on oral health affects the degree of decline in their quality of life that results from oral health deterioration.

CERQual assessment of confidence in finding 4.14: Low confidence due to moderate concerns about adequacy, and serious concerns about coherence and relevance

Supporting studies 4.14: (Donnelly, 2011; Niesten *et al.*, 2012; Niesten *et al.*, 2013)

Quote 4.14 (dependent adult): *"It is easy for me to accept that my teeth are getting worse. I don't really mind. It is something you can't change anyway"* (Niesten *et al.*, 2012)

Finding 4.15: The amount of value placed by dependent adults on oral health affects their desire to seek professional dental care and the desire to receive or undertake daily oral care.

CERQual assessment of confidence in finding 4.15: Moderate confidence due to minor concerns about coherence and adequacy, and moderate concerns about relevance

Supporting studies 4.15: (MacEntee, 1999; Paulsson *et al.*, 2002; Hui, 2008; Donnelly, 2011; Niesten *et al.*, 2012; Lindqvist *et al.*, 2013; Niesten *et al.*, 2013; McKibbin *et al.*, 2014; Gilmour *et al.*, 2016)

Quote 4.15.a (dependent adult): *"My teeth don't interest me … I only rinse them [dentures] when something gets underneath, and that's it … I don't know if a dentist could help me, I don't care."* (Niesten *et al.*, 2013)

Quote 4.15.b (caregiver): *"Oh, I have no idea what [the residents'] priorities are … they must make it very low because their teeth are in such bad condition that they certainly haven't attended to them for many years."* (MacEntee, 1999)

Quote 4.15.c (dependent adult): *"I am sure … if you would feel so miserable, you wouldn't feel like … fixing [your teeth] up or whatever you had to do."* (Donnelly, 2011)

4.5 Discussion

At the beginning of this discussion, a brief summary of the findings is provided to improve readers' comprehension of a new conceptual model created based on the outcomes of this qualitative evidence synthesis (Figure 4.3). Then, a discussion of the findings of this synthesis is presented for each theme separately. The discussion focuses on the similarities and differences between the newly established conceptual model and the oral health models that have been identified during establishing the *a priori* framework (Table 4.2). This was mainly undertaken to reveal any potential differences in how oral health is perceived by dependent adults and other populations. Furthermore, a description of how the new conceptual model has evolved from the *a priori* framework was reported (Table 4.3). Moreover, the findings of this synthesis were matched and contrasted with the wider scientific literature by comparing the findings of this synthesis with the relevant theories and studies. This was performed to explain, support and challenge the findings of this synthesis. Lastly, the strengths and limitations of this qualitative evidence synthesis are discussed.

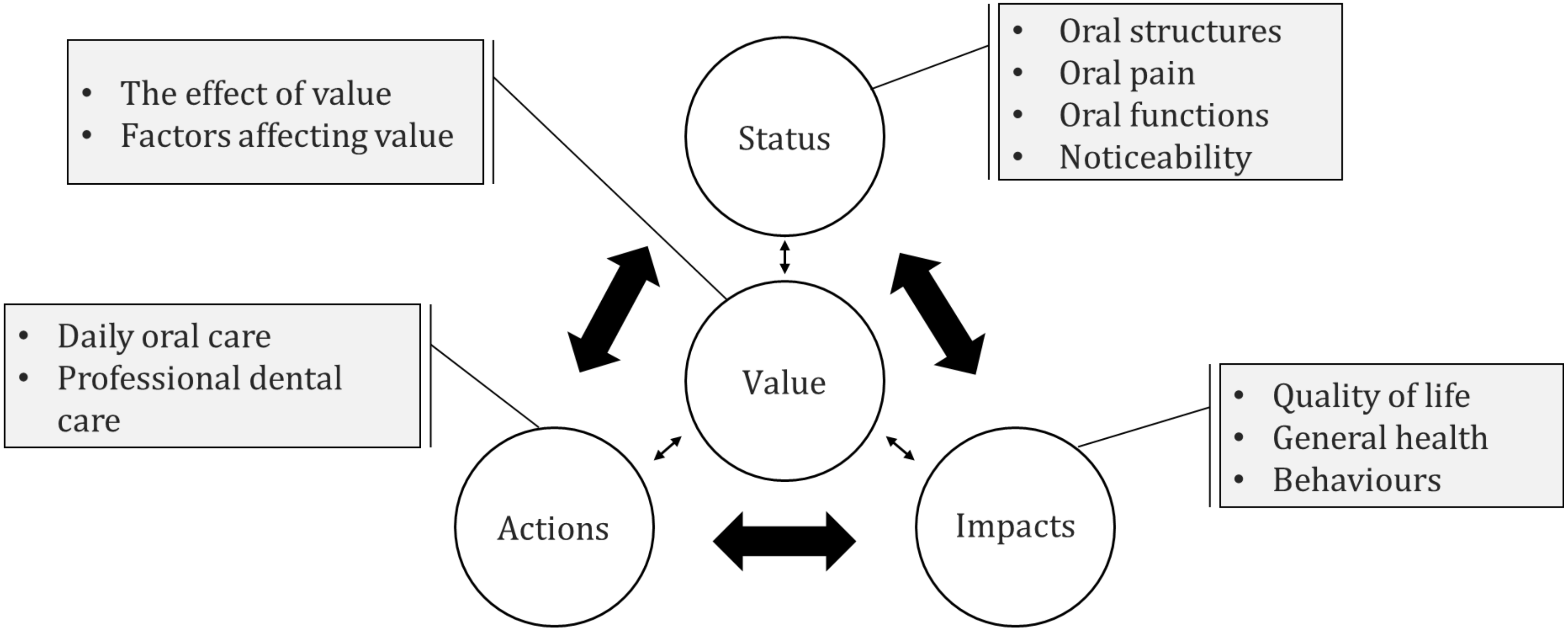

Figure 4.3: The new conceptual model of oral health in dependent adults.

4.5.1 Summary of the main findings

Based on the findings of this qualitative evidence synthesis, a conceptual model of oral health in dependent adults has been established, and it consists of four main components (Figure 4.3). The first component is oral health status, which has been shown to be a multidimensional construct that consists of four main domains. While these domains are not mutually exclusive, they are used by dependent adults and their caregivers as criteria to define and evaluate dependent adults' oral health status. These four domains (criteria) are intactness and cleanliness of oral structures, oral pain and discomfort, oral functions and noticeable oral health aspects. Dependent adults and their caregiver have reported a wide range of oral health problems in dependent adults that are related to these four domains. In addition, they have suggested a number of potential causes for these problems.

Deterioration in the oral health status impacts three main aspects of dependent adults' life: quality of life, behaviours and general health. Several direct and indirect means were suggested to explain how the status of oral health impacts on the quality of life in dependent adults. First, oral health status affects how dependent adults evaluate themselves (self-worth) and how they are evaluated by others during social interaction (social worth). Self-worth and social worth influence dependent adults' self-esteem, dignity and pride, which subsequently impact on their overall quality of life. In addition, pleasure from eating food attained from the ability to eat has another effect on dependent adults' quality of life. Furthermore, suffering from oral pain and discomfort directly affects dependent adults' quality of life in a negative way. Another negative effect of oral pain and discomfort on dependent adults is by altering their behaviours and ability to cooperate. Finally, deterioration in the status of oral health affects dependent adults' general health and mortality through decreasing body nutritional status and initiating aspiration pneumonia.

There are two main actions that are undertaken by/for dependent adults in relation to their oral health, namely daily and professional oral care. The main motive for dependent adults and their caregivers to undertake daily oral care is to prevent the deterioration of oral health status and the impacts of this deterioration. On the other hand, professional dental care is mainly sought to restore oral health problems after they occur.

The three previously described components of the conceptual model (i.e. status, impacts and care actions) are influenced by the amount of value that dependent adults place on oral health. The relationship between the value of oral health and the other components is proportional in nature. Thus, a decrease in the value of oral health would change how dependent adults define and evaluate their oral health by considering fewer criteria (domains) when making this evaluation. For example, when there is an extreme reduction in the value of oral health, dependent adults may only consider oral pain and discomfort to define and evaluate their overall oral health. In addition, a decrease in the value would reduce the degree of impact that oral health status has on dependent adults' quality of life and on their desire to initiate oral care. There are several factors that change the oral health value in dependent adults. These include the status of dependent adults' general health and overall quality of life. In addition, dependent adults' ability to perform or receive oral care is another factor. Furthermore, the oral health status of dependent adults' peers plays a role in determining the value. Lastly, original beliefs and attitudes towards oral health before dependency would still influence the value of oral health in dependent adults.

4.5.2 Oral health status theme discussion

Oral health status in dependent adults is a multidimensional construct that consists of four major domains. The first domain is the intactness and cleanliness of oral structures, and this synthesis revealed that dependent adults experience a plethora of problems that are related to this domain. This plethora of oral structures' problems is in line with other clinical studies that have demonstrated the worsening in adults' oral health conditions after becoming dependent (da Cruz *et al.*, 2014; Karki *et al.*, 2015). Even though dependent adults and their caregivers have reported some of the causes of these problems, they were not comprehensive or detailed in these reports, which could be attributed to their limited knowledge of dentistry and oral health (Reis *et al.*, 2011; Horne *et al.*, 2015).

In contrast to the newly established model, the intactness and cleanliness of oral structures domain in many previous models is divided into smaller components and a rigid linear relationship between these components was described (Locker, 1988; Wilson and Cleary, 1995; Gilbert *et al.*, 1998). For example, Locker (1988) described in his oral health model how a "disease" such as caries or periodontitis could result in tooth loss "impairment" that might subsequently affect patient's chewing ability "functional limitation". The detailed description of the components and their relationships in these models could be due to the large influence that has been exerted on them by the biomedical paradigm during their development (Wade and Halligan, 2004). On the other hand, the holistic view of oral structures in the new model might be due to the utilisation of an existential approach by incorporating the views and perspectives of dependent adults and their caregivers. Thus, the holistic view may suggest that a detailed description of oral structures' components and their relationships is not important and significant from the participants' point of view in the included studies (Berg and Sarvimäki, 2003). The holistic view could also be due to the participants' limited scientific knowledge of oral health (Reis *et al.*, 2011; Horne *et al.*, 2015). In fact, oral health models that were developed utilising a similar existential approach (e.g. MacEntee (2006) and Brondani *et al.* (2007) models) have provided a parallel holistic view without suggesting any relationship. As a consequence of this holistic view, data from several codes in the *a priori* framework (i.e. health condition, function, structure and hygiene) have been combined together to create the domain of oral structures.

This synthesis has also revealed that oral pain and oral functions are two of the essential domains of oral health in dependent adults. In addition, it showed that dependent adults could be susceptible to experiencing oral health problems in relation to these two domains. Several clinical studies are in line with the last finding and have shown oral pain and oral dysfunctions to be significant problems for dependent adults (Yoon *et al.*, 2018; Nakagawa and Matsuo, 2019).

Changes were made to the names and scopes of the *a priori* framework's original codes that are related to oral pain and oral functions. Even though most of the previous oral health models have used terms such as pain, comfort and discomfort to describe oral pain, Wilson and Cleary (1995) in their model were more comprehensive by using the term "symptoms" to encompass the full patients' perceptions about their physical, emotional and cognitive state. Thus, in an effort to be more comprehensive the term "symptoms" was used in the *a priori* framework. However, it was clear as the synthesis progressed that there was a large overlap between the scope of the "symptoms" code and other codes (e.g. "structure", "function", "hygiene" codes in Table 4.3). Therefore, the name and the scope of this code were changed to be about oral pain and discomfort.

The data regarding oral functions were originally coded using the "activity" code, which its name was changed later to "oral functions" to improve the accuracy of terminology.

The domain of noticeable oral health aspects is a unique domain that has not been described in any of the previous oral health models. Thus, it was established through thematic analysis of data that were not captured by the *a priori* framework. This domain might not exist in the other models because (from a biomedical point of view) it is only a subset of the oral structures' domain. It might be that as adults became dependent and start to place less value on oral structures domain (Finding 4.11), they begin to separate what they perceive to be the most important aspects of the oral structures domain (i.e. aspects that could be noticed by others) to form this new domain. In fact, the only model (i.e. from those used to establish the *a priori* framework) that touched on the concept of noticeable oral health aspects was originally developed based on inputs from the older people who usually are at higher risk of being dependent than the populations of the other models (MacEntee *et al.*, 1997; MacEntee, 2006).

4.5.3 Oral health impact theme discussion

Three main aspects of dependent adults' life (beyond the mouth) were found to be affected by the status of their oral health in this synthesis (i.e. quality of life, general health and behaviours). Quality of life in the context of this synthesis means the subjective well-being of how happy and/or satisfied individuals are with their life. Even though the association between the worsening in the status of oral health and the decline in the quality of life have been established for a long time (Sischo and Broder, 2011; Bennadi and Reddy, 2013), it was only explicitly stated in one of the previous oral health models (Wilson and Cleary, 1995). Other models have only discussed the concept of oral health-related quality of life without being a distinct component in them (Locker, 1988; MacEntee, 2006; Brondani *et al.*, 2007). This may be because most of these models did not consider the patients' views and experiences, and therefore they have failed to appreciate the significance of quality of life in relation to oral health.

In contrast to the newly established model, none of the previous oral health models have suggested means by which oral health impacts on people's quality of life. This could demonstrate one of the advantages of the qualitative evidence synthesis, which has allowed to hypothesise these means by achieving a greater understanding of the phenomenon through accessing and analysing a large volume of data. In this synthesis two aspects of oral health were found to impact directly on dependent adults' quality of life, namely oral pain and eating ability. In fact, many studies are in agreement with this finding and have verified the effect of oral pain and eating ability on the quality of life (Shueb *et al.*, 2015; Govindaraju *et al.*, 2018; Svensson *et al.*, 2018). On the other hand, two indirect means were suggested in this synthesis to explain how oral health status affects dependent adults' quality of life (i.e. through self-worth and social worth). To the research team's knowledge, this synthesis is the first study to propose these two means. Thus, further studies are needed to further explore these two hypothesised means in different populations of dependent adults.

Most of the models forming the *a priori* framework have explicitly described the impact of oral health status on people's social interactions, and therefore they have contributed in creating the "participation" code in the *a priori* framework (Locker, 1988; Gilbert *et al.*, 1998; WHO, 2001; MacEntee, 2006; Brondani *et al.*, 2007). Nonetheless, the data coded using this code later became part of the quality of life subtheme because evidence suggest that the disruption in dependent adults' social interaction is not a direct consequence of oral health problems but a strategy that is undertaken by them to maintain their quality of life through preserving their social worth (Finding 2.8).

Two aspects of dependent adults' general health were proposed to be influenced by the status of their oral health in this synthesis. One of the reported consequences is the incidence of aspiration pneumonia due to oral hygiene deterioration. Aspiration pneumonia can be defined as inflammation in the lungs' air sacs that resulted from a macroaspiration or microaspiration event (DiBardino and Wunderink, 2015). While poor oral hygiene *per se* does not cause aspiration pneumonia in normal individuals, there are several factors that can increase the risk of aspiration pneumonia incidences due to deterioration in oral cleanliness (DiBardino and Wunderink, 2015). These risk factors include swallowing dysfunction, age, altered mental status and oesophageal motility disorders (DiBardino and Wunderink, 2015; Mandell and Niederman, 2019). Many of these risk factors are highly prevalent in dependent adults due to age-related causes (van der Maarel-Wierink *et al.*, 2011; DiBardino and Wunderink, 2015). In fact, several clinical studies have verified the strong link between oral hygiene level and aspiration pneumonia incidences in dependent older adults (Shi *et al.*, 2013; Van Der Maarel-Wierink *et al.*, 2013; Hua *et al.*, 2016). This could explain why in this synthesis, this finding was only reported by the studies that have included adults with age-related dependency.

In this synthesis, the nutritional status of the dependent adults is the second aspect of their general health that has been suggested to be affected by the oral health status. Many observational and interventional studies are in line with this finding and have confirmed the association between poor oral health status and malnutrition in dependent adults (Nordenram *et al.*, 2001; Chai *et al.*, 2006; Hugo *et al.*, 2016). The malnutrition in these studies were reported based on the dependent adults' lower level of blood serum albumin concentration and lower body mass index (Nordenram *et al.*, 2001; Chai *et al.*, 2006).

Other possible impacts of oral health status deterioration on general health such as heart diseases, diabetes, arthritis and kidney diseases were not reported in this synthesis (Hajishengallis, 2015; Hein and Williams, 2017). This could be because almost all of the findings regarding the impact of oral health on general health were only reported by the dependent adults' caregivers, who may not have an extensive knowledge of oral health and dentistry (Göstemeyer *et al.*, 2019). This might also indicate that dependent adults in their everyday life experiences may not perceive the impact of oral health status on their general health.

The impact of oral health status on general health was only considered in the two most recently developed models among those used to establish the *a priori* framework (MacEntee, 2006; Brondani *et al.*, 2007). This may reflect the common belief among the researchers at the time of developing the other older models that oral health has no or negligible effect on people's general health (Hein and Williams, 2017). Nonetheless, not including the concept of general health in these models could be attributed to the models' developers concerns about the potential residual confounding bias in evidence supporting the association between oral health deterioration and general health decline (Humagain *et al.*, 2006; Scannapieco and Cantos, 2016).

The data that were coded using the "death" code from the *a priori* framework have been merged into the general health subtheme because there was a consensus in this synthesis that mortality is not a direct consequence to oral health deterioration but a consequence of more serious general health conditions that can occur due to oral health problems. In fact, the only paper among those used to establish the *a priori* framework that has suggested that "death" is one of the consequences of oral health deterioration, has also conceded that "death" is not a totally relevant consequence for most oral health problems (Locker, 1988).

Lastly, the concept that behaviours and ability to cooperate could be disturbed by oral pain and discomfort was a distinctive concept of this conceptual model, and thus was established through the thematic analysis of data. There is evidence that supports the notion that pain could induce aggression and challenging behaviours (Archer, 1989; Bruns *et al.*, 2003; Niel *et al.*, 2007). However, because this finding was only supported by studies that have included dependent adults with dementia, the disruptive behaviours could be a unique characteristic with this population (Ahn and Horgas, 2013; Van Dalen-Kok *et al.*, 2015). Actually, these disruptive behaviours may represent the way dependent adults with dementia express their pain when losing their ability to verbalise (Ahn and Horgas, 2013). In addition, neuropathological changes related to dementia could contribute to initiating these behaviours (Lai *et al.*, 2010). Thus, the reason this concept is not part of the *a priori* framework could be because it is not relevant to independent adults, who can verbalise their pain and seek resolution for it.

4.5.4 Oral health care theme discussion

Oral health care is a unique concept of this conceptual model that was not discussed in any of the previous oral health models. This may indicate that performing daily oral care and accessing professional dental care occupy a significant space in the dependent adults' minds in comparison to the populations of the other models. The higher attention that dependent adults give to oral care could be due to the challenges and barriers they face when performing or seeking oral care (Hearn and Slack-Smith, 2016; Göstemeyer *et al.*, 2019), which can be a significant contributing factor to an overall suboptimal oral care experience (Chan *et al.*, 2011; Miranda *et al.*, 2016).

While dependent adults undertake daily oral care to prevent oral health problems, professional dental care would not be sought by them unless an oral health problem was perceived to exist. This might be because dependent adults understand the important role of daily oral care in preventing oral health problems, but not fully appreciate the preventive role of regular visits to dental professionals. In fact, several studies showed that a routine dental check-up is one of the least frequently reported reasons for dental visits and this is mainly because of the lack of oral health awareness and knowledge

(Devaraj and Eswar, 2012; Wiener and Shockey, 2014). The role of knowledge on people's health behaviour is supported by the Health Belief Model theory (Rosenstock, 1974). The Health Belief Model is one of the earliest theories that explain patients' health-related behaviours and attitudes, and it has shown a validity in exploring oral health-related behaviours (Sulat *et al.*, 2018; Sanaei Nasab *et al.*, 2019). The theory suggests that for a health-related action to be undertaken by any person, it is necessary for that person to believe that he or she is susceptible to a serious health condition and to also believe that the undertake action is effective in preventing or resolving this condition (Hollister and Anema, 2004).

Nevertheless, the discrepancy between the perceived roles of daily oral care and professional dental care could have another explanation that is based on the Transtheoretical Model theory. This theory was developed in the mid-1970s, and it has been previously utilised to modify oral health-related behaviours (Hollister and Anema, 2004; Prochaska and Norcross, 2018). It states that people move along a predictable continuum when undertaking health-related action and this movement is mainly influenced by evaluating the costs and benefits of that action (Prochaska and Norcross, 2018). Thus, because dependent adults have been reported to face several barriers and challenges to access professional dental care (Hearn and Slack-Smith, 2016), the reason why dependent adults might not seek professional dental care for preventive purposes could be because they consider the costs of these visits to outweigh any potential benefits.

4.5.5 The value of oral health theme discussion

Most of the previous oral health models have appreciated the dynamic nature of oral health, and therefore acknowledged that many factors could affect the different components of the oral health models. For example, Wilson and Cleary (1995) and the WHO (2001) in their models described several personal and environmental factors that are not part of the "oral" health conditions but still influence the construct of "oral" health. Other models have even provided a more detailed explanation of such factors (MacEntee, 2006; Brondani *et al.*, 2007). However, none of these models have attempted to establish an overarching theme that could collectively describe these factors and their effects. Thus, the value of oral health theme in the new conceptual model is one of the novel findings of this qualitative evidence synthesis. Data that were coded using the "personal factors" code and the "environmental factors" code in the *a* *priori* framework were combined along with other thematically analysed data to form the theme of oral health value.

Even though dependent adults and their caregivers have reported different factors that could change the amount of value that dependent adults placed on oral health, the dependency itself seems to be the actual factor. This is because almost all of the reported factors could be considered as a cause of dependency (e.g. Finding 4.1) or as a dependency manifestation (e.g. Finding 4.7). Thus, it is evident that dependency does not only affect adults' ability to seek and undertaken oral care, which in turn negatively affects their oral health status and overall life, but also affects how they view and perceive the construct of oral health.

There are several theories in the health psychology field that could explain the suggested effect of dependency on the value of oral health and the effect of value on the other components of the new conceptual model. The Hedonic Treadmill Model theory suggest that unchanging adverse events in people's life (e.g. being dependent) does not have a persistence effect on their subjective well-being and quality of life (Diener *et al.*, 2006; Lucas, 2007). This is mainly attributed to people's ability to adapt to these events (Diener *et al.*, 2006). The Hedonic Treadmill Model theory is supported by many studies that have shown a low correlation between persistent adverse events and people's subjective well-being and quality of life (Lucas, 2007; Luhmann *et al.*, 2012). One of the suggested adaptation mechanisms is through "shifting intrapsychic criteria" by placing less significance on what causes deterioration in the quality of life in order to return to the original level of quality of life (Heyink, 1993). This could explain the dependent adults' attitude towards losing control over their oral health status and oral care by placing less value on them in order to maintain their quality of life. Another suggested adaptation mechanism is provided by the Social Comparison Theory, which states that people under threat would compare themselves to others in order to buffer against that threat (Cheng *et al.*, 2007). Thus, dependent adults may compare their oral health with their peers to facilitate acceptance of their reduced level of control upon their oral health and care, which is in line with Finding 4.8.

4.5.6 Strengths and limitations

This qualitative evidence synthesis, to the research team knowledge, is the first systematic review that investigated the phenomenon of oral health in dependent adults.

To achieve robust findings in this synthesis, several steps were undertaken to ensure the strength of methods applied. First, the methods used to search for primary qualitative studies were comprehensive, and therefore the chance of including all relevant studies was high. In addition, views and experiences of two expert groups (i.e. dependent adults and their caregivers) were considered in this synthesis, which allowed accounting and contrasting between two unique perspectives. Furthermore, all the steps in this synthesis were independently performed by two reviewers, which should minimise potential biases, and subsequently improve the internal validity of the synthesis. Finally, the GRADE-CERQual confidence assessment that was undertaken for each reported finding allowed making transparent and systematic decisions about each finding's accuracy in representing the phenomenon being investigated.

There are, however, a few limitations regarding this qualitative evidence synthesis that could have introduced potential biases, and subsequently threaten the validity of the produced conclusions. One limitation is the potential bias regarding where and on whom the included studies were conducted. For example, adults with age-related dependency were overrepresented in this synthesis because more than two-thirds of the included studies (i.e. 19 studies) were about them. Thus, it would be difficult to distinguish why some of the findings were only reported by this population. These findings could be relevant to all forms of dependency, but were not reported by the other dependent adults because they were not sufficiently represented in this qualitative evidence synthesis. Another potential limitation in this synthesis is that almost all of the included studies were conducted in well-developed countries with strong economic status. The course of adults' dependency could be different in countries that are less developed and with a weaker economy because of deficiency in their medical infrastructures, as well as the different age distribution of their populations. Lastly, the language bias in this synthesis cannot be overlooked. This synthesis was restricted to the English language because of reasons related to feasibility. Thus, not including studies that were published in other languages could result in not including studies with possibly different social perspectives.

4.6 Conclusion

This qualitative evidence synthesis has established a new conceptual model of oral health, which could provide a deeper and better understanding of the phenomenon of oral health in dependent adults. This synthesis revealed that oral health in dependent adults is a multidimensional construct that impacts on their quality of life, general health and behaviours. In addition, it showed the relationships between the oral health status and its impacts with oral care-related actions. Furthermore, it revealed that oral health in dependent adults is not a static construct because the value placed by them on oral health affects the different components of this conceptual model. This conceptual model could provide a starting point to guide the establishment of person-centred oral care assessment and interventions for dependent adults. In addition, it could help in examining the content validity of oral health measurement instruments.

Chapter 5. Evaluation of Measurement Properties, Interpretability and Feasibility of Instruments Measuring Oral Health and Orofacial Pain in Dependent Adults—A Systematic Review

5.1 Introduction

Those caring for dependent adults face a potentially challenging task in respect of oral healthcare, which is particularly the case if they are unable to easily identify the oral health problems of those who are dependent upon them (Göstemeyer *et al.*, 2019). This is supported by several reports from caregivers who have voiced their need for an oral health measurement instrument that could help them establish oral care plans for dependent adults (Hijii, 2003; Horne *et al.*, 2015; Andersson *et al.*, 2019). It is perhaps, therefore, no surprise that a number of measurement instruments have been specifically developed for this purpose (Chalmers and Pearson, 2005). However, because evidence about these instruments' performance is dispersed in the scientific literature, accessing this evidence may not be easy. This may negatively affect the caregivers' ability to reach a sound and scientific judgment about these instruments, which could partially explain why they have not been widely used in clinical settings (Flottorp *et al.*, 2013). A systematic review about these measurement instruments is, therefore, needed to identify the published evidence about these measurement instruments and establish an evidence-based decision about the best available ones (De Vet *et al.*, 2011, p. 275).

This systematic review was not limited to identifying and evaluating general oral health measurement instruments alone because it also included and evaluated those to measure orofacial pain. This was undertaken because the qualitative evidence synthesis in the previous chapter revealed that in extreme cases of dependency oral health in dependent adults may only be evaluated based on the presence or absence of pain.

5.2 Aim

To systematically identify measurement instruments that measure oral health (or orofacial pain) in dependent adults and evaluate these instruments' measurement properties, interpretability and feasibility.

5.3 Methods

5.3.1 Study design

This quantitative systematic review was conducted according to the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) principles

(Prinsen *et al.*, 2018). COSMIN is an initiative of international researchers of multidisciplinary specialities who aim to improve the process of evaluating and selecting health-related measurement instruments in the fields of research and clinical practice (Mokkink *et al.*, 2006). To achieve this aim COSMIN has developed and published a number of methods, guidelines and practical tools, which have been adopted and utilised in this systematic review.

Even though the COSMIN tools and guidelines were initially developed for evaluating and selecting patient-reported measurement instruments, the COSMIN steering committee has suggested that these tools and guidelines are relevant for all types of health-related measurement instruments (De Vet *et al.*, 2011). In addition, these tools and guidelines have been successfully used in previous studies to evaluate different types of health-related measurement instruments (Bartels *et al.*, 2013; Christian *et al.*, 2019).

This systematic review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement to improve the reporting style, transparency and clarity (Moher *et al.*, 2009).

5.3.2 Protocol and registration

The protocol of this systematic review that described its objectives and methods was established before carrying out the study. In addition, it was registered in the International Prospective Register of Systematic Reviews (PROSPERO) database. The registration number is CRD42017073404 (BaHammam *et al.*, 2017). Documenting and registering the protocol were taken in advance to reduce any potential *post hoc* biases.

5.3.3 Criteria for considering studies

The inclusion and exclusion criteria for selecting eligible studies in this systematic review followed the PICOS criteria, which are Participants, Interventions, Comparators, Outcomes and Studies (Pollock and Berge, 2018). However, the “Comparators” component was not considered during formulating the selection criteria because this component is not applicable for systematic reviews evaluating measurement properties, interpretability and feasibility of measurement instruments (Pollock and Berge, 2018).

Types of participants

Inclusion criteria

- Eighteen years or older
- Need or receive support/assistance due to a reduction in mental capacity or physical capability

Exclusion criteria

- Less than eighteen years old
- Participants are independent

Types of interventions

Inclusion criteria

- Measuring oral health or orofacial pain

Exclusion criteria

- Not measuring oral health or orofacial pain

Types of studies

Inclusion criteria

- Study published in the English language
- Study available in full text
- Study developed an original instrument to measure oral health or orofacial pain in dependent adults, or evaluate measurement properties, interpretability or feasibility of such an instrument
- No restrictions on the settings where the studies have been performed
- No restrictions on the study design types
- No restrictions on the publication date

Exclusion criteria

- Studies published in languages other than English. This was undertaken for feasibility reasons.
- Study that is not available in full text because usually there is not enough information about the study design in abstracts to make a precise judgement during the quality assessment step.
- Studies used an instrument of interest (i.e. measurement instrument evaluates oral health or orofacial pain in dependent adults) to validate an irrelevant instrument (i.e. measurement instrument that does not meet the inclusion criteria).

- Studies used an instrument of interest to evaluate the effectiveness of an intervention without explicitly assessing measurement properties, interpretability or feasibility. This exclusion was done because it is extremely difficult to identify all these studies in a systematic way. In addition, it is challenging to interpret the findings of validity and responsiveness from this type of studies because they are lacking in advance hypotheses regarding these properties (De Vet *et al.*, 2011).

Types of outcomes

Primary outcomes

The primary outcomes in this systematic review are measurement properties. A measurement property can be defined as a feature that is related to a measurement instrument and reflects its quality (Mokkink *et al.*, 2010c). The taxonomy, terminology and definitions of the measurement properties used in this systematic review are adopted from a Delphi study that was undertaken by the COSMIN team (Mokkink *et al.*, 2010c). The findings of this Delphi study were used over taxonomies from other studies because this Delphi study was the only one that was based on the consensus of a large group of international experts and focused on health-related measurement instruments (Lohr, 2002; Mokkink *et al.*, 2010c). According to this study, measurement properties of health-related measurement instruments could be classified and grouped into three main quality domains, which are validity, reliability and responsiveness (Mokkink *et al.*, 2010c).

Validity is the first domain and is formed by three measurement properties that are concerned with assessing the degree to which a measurement instrument is truly scoring the construct that is intended to measure (Mokkink *et al.*, 2010c):

- Content validity: “the degree to which the content of a measurement instrument is an adequate reflection of the construct to be measured.”
- Criterion validity: “the degree to which the scores of a measurement instrument are an adequate reflection of a gold standard.”
- Construct validity: “the degree to which the scores of a measurement instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the measurement instrument validly measures the construct to be measured.” Structural validity is

part of construct validity and is defined as "the degree to which the scores of a measurement instrument are an adequate reflection of the dimensionality of the construct to be measured." Furthermore, cross-cultural validity is another aspect of construct validity that is defined as "the degree to which the performance of the items on a translated or culturally adapted measurement instrument are an adequate reflection of the performance of the items of the original version of the measurement instrument."

Reliability is the second domain, which consists of three measurement properties that collectively assess the consistency of a measurement instrument in scoring unchanged construct under different conditions. The names and definitions of these three measurement properties are (Mokkink *et al.*, 2010c):

- Reliability: "the proportion of the total variance in the measurements which is because of "true"[1] differences among patients."
- Measurement error: "the systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured."
- Internal consistency: "the degree of the interrelatedness among the items."

The last domain of the measurement properties is responsiveness (to change), which consists of one measurement property that has the same name and is defined as "the ability of a measurement instrument to detect change over time in the construct to be measured" (Mokkink *et al.*, 2010c).

Secondary outcomes

Interpretability and feasibility are the two secondary outcomes that were considered in this systematic review. These two concepts are not measurement properties but still are important characteristics of measurement instruments that should be considered when evaluating them (Prinsen *et al.*, 2018).

- Interpretability: "the degree to which one can assign qualitative meaning, that is, clinical or commonly understood connotations to an instrument's quantitative scores or change in scores" (Mokkink *et al.*, 2010c).

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[1] According to the Classical Test Theory, any observation is composed of a "true" score (i.e. repressing the score that would be obtained from averaging scoring undertook for infinite number of times) and an error associated with it. Thus, "true" in this definition refer to change in the "true" score component.

- Feasibility is defined as how easy it is to apply a measurement instrument in its intended setting, which may include aspects such as time required for completion, financial cost and measurement instrument length (Prinsen *et al.*, 2018).

5.3.4 Search methods for identification of studies

The following comprehensive search methods were utilised to identify eligible studies.

Electronic bibliographic database searches:

Three electronic bibliographic databases were searched on the 9th of October 2017 and were later updated on the 1st of August 2019:

- MEDLINE via Ovid (1946 to August Week 1, 2019)
- CINAHL via EBSCO (1986 to August Week 1, 2019)
- Embase via Ovid (1974 to August Week 1, 2019)

The search strategies that have been used in these electronic bibliographic databases have focused on three key elements (Terwee *et al.*, 2009), which were driven from the review question, namely: the constructs of oral health and orofacial pain, dependent adults and measurement properties. The first search strategy was developed for the MEDLINE database using Medical Subject Headings (MeSH) terms and relevant keywords. Then, it was translated into the other databases taking into account the differences in thesaurus terms and syntax rules. The electronic bibliographic databases searches were restricted to English language only.

The "measurement properties" component of the MEDLINE search strategy was adopted from a previously developed methodological search filter, which has been demonstrated to be highly sensitive and able to retrieve more than 97% of studies related to measurement properties (Terwee *et al.*, 2009). In fact, the sensitivity of this search filter is considerably higher than other search filters with similar aim (Leeflang *et al.*, 2006; Ritchie *et al.*, 2007). A detailed description of the MEDLINE search strategy is shown in Appendix D.

Other methods used to identify relevant studies:

Other search methods have been utilised to identify potentially eligible studies that might have been missed during the electronic database searches:

Firstly, a bibliographic manual hand search was carried out for the included studies. In addition, citation searches for the included studies were carried out using Scopus and Web of Science citation indices.

Secondly, the following sources were also searched for grey literature on the 29th of August 2018:

- Cochrane Central Register of Controlled Trials (CENTRAL)
- Health Technology Assessment (HTA)
- Open Access Theses and Dissertations (OATD)
- OpenGrey

Finally, Scopus and Web of Science were searched using the name of the identified measurement instruments and their abbreviations from the previously described search methods to identify further studies for inclusion on the 8th of August 2019.

5.3.5 Selection process

Two reviewers independently screened the titles and abstracts of all studies identified from the previously described searches to select potentially eligible ones based on predetermined inclusion and exclusion criteria. The two reviewers are the PhD student, Fahad BaHammam (FB), and one of the supervisors, Dr Bana Abdulmohsen (BA). When there was a doubt regarding the eligibility of a study at this stage, it was selected, and the final decision was made after screening the full text.

After retrieving the full texts of all studies identified as potentially eligible, the studies' full texts were subjected to the same inclusion/exclusion evaluation process to determine the relevant studies for inclusion by the two reviewers (FB & BA) independently. Disagreements at this stage were resolved through discussion between the two reviewers (FB & BA) and when necessary with another supervisor Prof Giles McCracken (GM).

5.3.6 Quality assessment

Quality assessment of the included studies' methods was undertaken independently by two reviewers (FB & BA) using the COSMIN Risk of Bias checklist (Mokkink *et al.*, 2018). The COSMIN Risk of Bias checklist consists of 10 boxes. The first box evaluates the quality of the method used to develop a measurement instrument, while the other nine boxes evaluate the quality of the methods used to assess the measurement properties of that instrument. Each box is evaluated by assessing 3 to 35 items. The evaluation's score for each item could be one of four scores, which are very good, adequate, doubtful or inadequate (Mokkink *et al.*, 2018). The COSMIN Risk of Bias checklist was developed based on the findings of a large international Delphi study and evidence has been provided to support its validity and its adequate inter-rater agreement (Mokkink *et al.*, 2010a; Mokkink *et al.*, 2010b).

The COSMIN checklist is a modular tool, which means that only relevant boxes are completed for each study based on which properties were evaluated in that study (Terwee *et al.*, 2012). In addition, a box could be completed more than once for a study if the study evaluated a measurement property in multiple populations and separately reported the evaluations' results for each population (Terwee *et al.*, 2012). Thus, agreement between the two reviewers (FB & BA) was achieved regarding which boxes should be completed and how many times prior to starting the quality assessment.

The "worst score counts" method was used when evaluating each box so that the overall score for a particular box was determined by the lowest rating of any item in that box (Terwee *et al.*, 2012). In the case of any disagreement, the decision was made through discussion between the two reviewers (FB & BA) and with the third reviewer (GM) where necessary.

5.3.7 Data extraction

Data extraction was done independently by two reviewers (FB & BA) using a predesigned form in the Microsoft Excel ® software. The predesigned form was based on the COSMIN data collection form, which was published on their website (COSMIN, 2018). Any disagreement was resolved through discussion between the two reviewers (FB & BA) and with the third reviewer (GM) where necessary. Information that was extracted from the included studies was about:

- Participants' characteristics
- Instruments' characteristics
- Findings of instruments' interpretability
- Findings of instruments' feasibility
- Results on instruments' measurement properties

5.3.8 Content comparison

Domains and aspects that are evaluated in the identified measurement instruments were compared in order to evaluate how these instruments vary in evaluating the constructs of oral health and orofacial pain in dependent adults. While this comparison is not part of the main data synthesis process, it was undertaken because it could help in evaluating the measurement instruments by exploring their comprehensiveness.

5.3.9 Data synthesis

Data synthesis in this systematic review was undertaken through a number of steps.

Rating the measurement properties' results

The results on each measurement property from each study were rated using predetermined criteria that were adapted from Terwee *et al.* (2007) and Terwee *et al.* (2018). Results on measurement properties were rated as either sufficient, insufficient or indeterminate. The adapted criteria used for the rating are presented in Appendix E.

It must be noted that any included study could have evaluated a certain measurement property several times in the same population or in more than one population. Several evaluations that were undertaken in multiple populations were considered as different studies and each evaluation was rated separately. On the other hand, multiple evaluations that were undertaken on the same population were considered as a single study and therefore all different evaluations were collectively rated at once. To resolve any inconsistency in the results in the last scenario, a sufficient or insufficient rating was assigned if 75% or more of the results were in accordance with sufficient or insufficient criteria. Otherwise, an indeterminate rating was assigned.

Summarising the evidence

The measurement properties' ratings from the last step were summarised to come to an overall evaluation of each measurement property for each identified measurement instrument from all contributing studies. If ratings of an instrument's measurement property from different studies were consistent, the same rating was assigned for the overall rating of the instrument's measurement property. However, if ratings of an instrument's measurement property from different studies were inconsistent, an exploration for an explanation was undertaken to produce overall ratings that are based on consistent subgroups (i.e. the subgroups could be based on the differences from populations or methods). If no explanation was found for the inconsistency, the overall rating of the instrument's measurement property was based on the majority of consistent results (≥75%). If no majority of consistent results could be identified, ratings were not summarised, and an overall indeterminate rating was given.

Grading the quality of the evidence

The quality of evidence supporting the overall rating for each measurement property per measurement instrument was graded based on an adapted version of the Grading of Recommendation Assessment, Development and Evaluation (GRADE) approach (Akl *et al.*, 2013; Prinsen *et al.*, 2018). This grading process has four potential outcomes:

- High quality level: strong confidence that the true measurement property lies close to that of the measurement property's summarised result;
- Moderate quality level: moderate confidence that the true measurement property lies close to that of the measurement property's summarized result, with a possibility that it is substantially different;
- Low quality level: limited confidence that the true measurement property lies close to that of the measurement property's summarized result and it may be substantially different;
- Very low quality level: very limited confidence that the true measurement property lies close to that of the measurement property's summarized result and it is likely to be substantially different.

The level of evidence for an overall rating was always graded as being of a high quality level and was only downgraded where there was a concern in one or more of the GRADE factors.

- Risk of bias: it was evaluated based on the findings from the COSMIN Risk of Bias checklist. Table 5.1 summarises the criteria to downgrade the quality level.
- Inconsistency: level of evidence was downgraded by one level when unexplained inconsistent results were summarised from one study and it was downgraded by two levels when unexplained inconsistent results were summarised from more than one study.
- Imprecision: it refers to the total number of samples in all studies contributing to an overall rating. Level of evidence was downgraded by one level when the total sample size was less than 100 and it was downgraded by two levels when the total sample size was less than 50.

- Indirectness: level of evidence was downgraded by one level when part of the sample in the contributing studies did not meet the inclusion criteria of this systematic review.

Risk of bias	Downgrading	Criteria
No	No	Multiple studies of at least adequate quality, or one study of very good quality
Serious	1 level	Multiple studies of doubtful quality, or one study of adequate quality
Very serious	2 levels	Multiple studies of inadequate quality, or one study of doubtful quality
Extremely serious	3 levels	One study of inadequate quality available

Table 5.1: Criteria for downgrading risk of bias.

Best evidence synthesis

Best evidence synthesis was carried out by integrating the overall rating for each measurement property per measurement instrument with its quality level of evidence that was established utilising the GRADE approach.

5.4 Results

5.4.1 Results of literature searches

The literature search in this systematic review retrieved 11441 studies. Searches performed in the electronic database identified 9206 studies (2422 MEDLINE, 5435 Embase and 1349 CINAHL) and the other search methods retrieved another 2235 studies. After duplicates were removed, and titles and abstracts and then full texts were screened, 17 studies met the inclusion criteria and were therefore included. A detailed list of excluded studies with the reasons of exclusion can be found in Appendix F. Figure 5.1 presents a PRISMA flow diagram adapted from Moher *et al.* (2009), which summarises the retrieval, screening and selection processes.

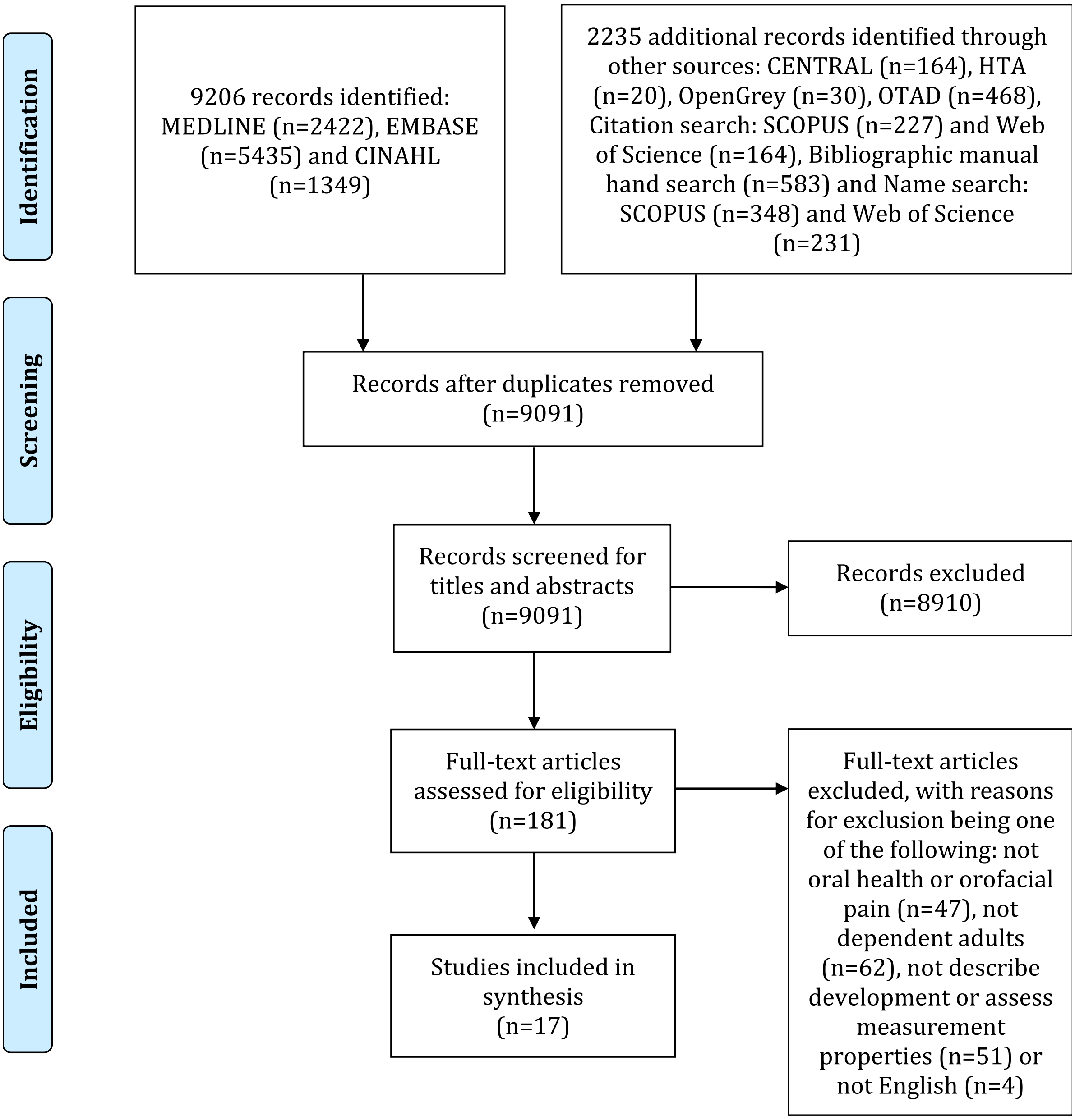

Figure 5.1: PRISMA flow diagram for retrieval, screening and selection processes in the quantitative systematic review.

5.4.2 Characteristics of included studies and measurement instruments

The 17 included studies in this systematic review can be divided into two groups. The first group consist of 12 studies that described the development and measurement properties' evaluation of eight oral health measurement instruments (Table 5.2). On the other hand, the second group consist of five studies that described the development and measurement properties' evaluation of three orofacial pain measurement instruments (Table 5.3). In general, most of the included studies were conducted in hospital or care home. In addition, they usually evaluated the construct validity or reliability. Oral health measurement instruments were usually evaluated in adults with age-related or physical-related dependency. On the other hand, orofacial pain measurement instruments were only evaluated in dependent adults due to dementia.

Table 5.4 and Table 5.5 show the main characteristics of the identified oral health and orofacial pain measurement instruments, respectively. All the identified measurement instruments were clinician-reported and were mostly developed to guide oral care planning for hospitalised patients and care home residents. These instruments were developed to be used by dentists, nursing staff or health care workers. The number of items in these instruments ranged from two to 64.

The contents of the included oral health and orofacial pain measurement instruments are shown in Table 5.6 and Table 5.7, respectively. The aspects that are measured by the oral health measurement instruments were arranged into four main domains according to the newly established conceptual model from the last chapter. The aspects measured by the orofacial pain measurement instruments were arranged into four domains according to the domains reported in the included studies (De Vries *et al.*, 2016; Toxopeus *et al.*, 2016).

Instrument name	Author (Year)	Country	Setting	Study aim	Dependency cause	Sample characteristics
BOHSE	Kayser-Jones *et al.* (1995)	USA	Care homes	Development and reliability assessment	Age-related	**Selection method:** convenience sample **Size:** 100 **Age average (range):** 82 (50–106) years **Gender (% female):** 50%
MPS	Henriksen (1999)	Norway	Care homes	Reliability assessment	Age-related and mental-related	**Selection method:** NR **Size:** • Study (A): 24 • Study (B): 20 **Age average (range):** • Study (A): 84 (73–99) years • Study (B): 88 (75–99) years **Gender (% female):** • Study (A): 83%, • Study (B): 80%

Instrument name	Author (Year)	Country	Setting	Study aim	Dependency cause	Sample characteristics
THROAT	Dickinson *et al.* (2001)	UK	Hospital	Development and reliability assessment	Physical-related	**Selection method:** consecutive sample **Size:** 50 **Age average (range):** 84 (NR) years **Gender (% female):** 52%
	Mckenzie (2015)	UK	Hospital	Construct validity assessment	Physical-related	**Selection method:** consecutive sample **Size:** 32 **Age average (range):** 77 (43–94) years **Gender (% female):** 56%
ROAG	Andersson *et al.* (2002)	Sweden	Hospital	Development and reliability assessment	Physical-related	**Selection method:** consecutive sample **Size:** 133 **Age average (range):** 81 (61–96) years **Gender (% female):** 64%
	Konradsen *et al.* (2014)	Denmark	Hospital	Reliability assessment	Physical-related	**Selection method:** consecutive sample **Size:** 148 **Age average (range):** 75 (NR) years **Gender (% female):** 55%

Instrument name	Author (Year)	Country	Setting	Study aim	Dependency cause	Sample characteristics
OHAT	Chalmers *et al.* (2005)	Australia	Care homes	Development, construct validity and reliability assessment	Age-related	**Selection method:** consecutive sample **Size:** 455 **Age average (range):** 82 (NR) years **Gender (% female):** NR
	Simpelaere *et al.* (2016)	Belgium	Care homes and hospital	Reliability assessment	Age-related and physical-related	**Selection method:** consecutive and convenience sample **Size:** 132 **Age average (range):** 84 (62–101) years **Gender (% female):** 72%
	Klotz *et al.* (2020)	Germany	Care homes	Reliability assessment	Age-related	**Selection method:** NR **Size:** 18 **Age average (range):** 82 (NR) years **Gender (% female):** 61%
OHI	Liétard *et al.* (2013)	France	Care homes	Development	Age-related	Not applicable

Instrument name	Author (Year)	Country	Setting	Study aim	Dependency cause	Sample characteristics
OAS	Yanagisawa *et al.* (2017)	Japan	Care homes	Development, and reliability assessment	Age-related	**Selection method:** self-selecting sample **Size:** 45 **Age average (range):** NR (NR) **Gender (% female):** NR
OHSTNP	Tsukada *et al.* (2017)	Japan	Care home	Development, and reliability assessment	Age-related	**Selection method:** convenience sample **Size:** 57 **Age average (range):** 86 (NR) years **Gender (% female):** 88%

- BOHSE = Brief Oral Health Status Examination, MPS = Mucosal-Plaque Score, THROAT = The Holistic and Reliable Oral Assessment Tool, ROAG = Revised Oral Assessment Guide, OHAT = Oral Health Assessment Tool, OHI = Oral Health Index, OAS = Oral Assessment Sheet, OHSTNP= Oral Health Screening Tool for Nursing Personnel
- NR = Not Reported

Table 5.2: Characteristics of the studies that described the development and evaluation of oral health measurement instruments.

Instrument name	Author (Year)	Country	Setting	Study aim	Dependency cause	Sample characteristics
FACS	Hsu *et al.* (2007)	USA	Dental clinics	Development, construct validity and responsiveness assessment	Dementia	**Selection method:** convenience sample **Size:** 10 **Age average (range):** 86 (NR) years **Gender (% female):** 80%
MOBID	Toxopeus *et al.* (2016)	Netherlands	Care home	Reliability assessment	Dementia	**Selection method:** consecutive sample **Size:** 11 **Age average (range):** 88 (69–97) years **Gender (% female):** 91%
OPS-NVI	De Vries *et al.* (2016)	Netherlands	Care homes	Reliability assessment	Dementia	**Selection method:** NR **Size:** 153 **Age average (range):** 83 (64–102) years **Gender (% female):** 71%
	Delwel *et al.* (2018a)	Netherlands	Care homes and hospital	Construct validity and reliability assessment	Dementia	**Selection method:** NR **Size:** 348 **Age average (range):** 83 (NR) years **Gender (% female):** 66%
	van de Rijt *et al.* (2019)	UK	Hospitals	Construct validity assessment	Dementia	**Selection method:** NR **Size:** 56 **Age average (range):** 84 (70–97) years **Gender (% female):** 59%

- FACS = Facial Actions Coding System, MOBID = Mobilization–Observation–Behaviour–Intensity–Dementia for mouth care, OPS-NVI = Orofacial Pain Scale for Non-Verbal Individuals
- NR = Not Reported

Table 5.3: Characteristics of studies that described the development and evaluation of orofacial pain measurement instruments.

Instrument name	Language	Number of items	Scale type	Instrument type	Scoring algorithm	Instrument aim	Users	Target population
BOHSE	English	10	3-point	Clinician-reported	Simple sum	Oral care planning	Nursing staff	Care home residents
MPS	English Norwegian	2	4-point	Clinician-reported	Simple sum	Group assessment	Health care workers	Care home residents
THROAT	English	9	4-point	Clinician-reported	Not applicable	Oral care planning	Nursing staff	Hospitalised patients
ROAG	English Danish Swedish	8	3-point	Clinician-reported	Simple sum	Oral care planning	Nursing staff	Hospitalised patients
OHAT	English German	8	3-point	Clinician-reported	Simple sum	Oral care planning	Health care workers and Speech language therapists	Care home residents and hospitalised patients
OHI	English French	8	Dichotomous	Clinician-reported	Simple sum	Oral care planning	Nursing staff	Care home residents
OAS	English Japanese	9	3-point	Clinician-reported	Simple sum	Oral care planning	Health care workers	Care home residents
OHSTNP	English Japanese	12	3-point	Clinician-reported	Simple sum	Oral care planning	Nursing staff and health care workers	Care home residents

Table 5.4: Main characteristics of the identified oral health measurement instruments.

Instrument name	Language	Number of items	Scale type	Instrument type	Scoring algorithm	Instrument aim	Users	Target population
FACS	English	6	Not applicable	Clinician-reported	A FACS score consisted of adding the duration of eye closing to the outcome of multiplying other items' intensity by their durations	Oral care planning	Dentists	Elderly with communication difficulties
MOBID	English	3	Dichotomous	Clinician-reported	Not applicable	Oral care planning	Dentists	Elderly with communication difficulties
OPS-NVI	English Dutch	64	Dichotomous	Clinician-reported	Simple sum	Oral care planning	Dentists	Elderly with communication difficulties

Table 5.5: Main characteristics of the identified orofacial pain measurement instruments.

Domains	Aspects	BOHSE	MPS	THROAT	ROAG	OHAT	OHI	OAS	OHSTNP
Intactness and cleanliness	Lips	●		●	●	●			●
	Tongue	●		●	●	●		●	●
	Gingiva	●	●	●	●	●	●	●	●
	Palate	●	●	●	●	●			●
	Floor of the mouth	●	●	●	●	●			●
	Cheek mucosa	●	●	●	●	●			●
	Saliva	●		●	●	●		●	●
	Lymph nodes	●							
	Teeth	●	●	●	●	●	●	●	●
	Dentures	●		●	●	●	●	●	●
	Occlusal units	●						●	
Functions	Mouth opening							●	
	Tongue thrusting							●	●
	Cheeks puffing								●
	Chewing							●	●
	Swallowing				●				●
	Speaking				●				●
Noticeability	Bad odour			●		●		●	●
Pain	Pain					●			

Table 5.6: Content of the identified oral health measurement instruments.

Domains	Aspects	FACS	MOBID	OPS-NVI
Facial expression	Frowning	●	●	●
	Narrowing eyes	●		●
	Closing eyes	●	●	●
	Nose wrinkling	●		
	Raising upper lip	●		●
	Tightening mouth or lips		●	●
	Opening mouth			●
	Cheek raising	●		
	Grimacing		●	
Body Movements	Guarding		●	●
	Resisting care		●	●
	Freezing		●	
	Crouching		●	
	Rubbing			●
	Restlessness			●
Vocalizations	Screaming		●	●
	Groaning		●	●
	Pain-related words		●	●
	Offensive words			●
	Gasping		●	
Specific behaviours	Restricting jaw movement			●
	Refusing prosthetics			●
	Drooling			●

Table 5.7: Content of the identified orofacial pain measurement instruments.

5.4.3 Methodological quality findings

The methodological quality of all included studies ranged from very good to inadequate. Most of the oral health measurement instruments' studies have shown a doubtful methodological quality and only one study has shown very good methodological quality. On the other hand, adequate and doubtful evaluations were the most common evaluations among orofacial pain measurement instruments studies. The methodological quality of oral health measurement instruments studies and orofacial pain measurement instruments studies is shown in Table 5.8 and Table 5.9, respectively. It must be noted that the methodological quality was presented only for the measurement properties that have been evaluated (i.e. construct validity and reliability for oral health measurement instruments in Table 5.8; and construct validity, reliability and responsiveness for orofacial pain measurement instruments in Table 5.9).

Instrument name	Study	Construct validity	Reliability
BOHSE	Kayser-Jones *et al.* (1995)	NA	Doubtful
MPS	Henriksen (1999) (A)	NA	Doubtful
	Henriksen (1999) (B)	NA	Doubtful
THROAT	Dickinson *et al.* (2001)	NA	Adequate
	Mckenzie (2015)	Adequate	NA
ROAG	Andersson *et al.* (2002)	NA	Doubtful
	Konradsen *et al.* (2014)	NA	Doubtful
OHAT	Chalmers *et al.* (2005)	Inadequate	Doubtful
	Simpelaere *et al.* (2016)	NA	Very good
	Klotz *et al.* (2020)	NA	Doubtful
OHI	Liétard *et al.* (2013)	NA	NA
OAS	Yanagisawa *et al.* (2017)	NA	Doubtful
OHSTNP	Tsukada *et al.* (2017)	NA	Doubtful

Table 5.8: Methodological quality of oral health measurement instruments studies.

Instrument name	Study	Construct validity	Reliability	Responsiveness
FACS	Hsu *et al.* (2007)	Adequate	NA	Doubtful
MOBID	Toxopeus *et al.* (2016)	NA	Doubtful	NA
OPS-NVI	De Vries *et al.* (2016)	NA	Adequate	NA
	Delwel *et al.* (2018a)	Doubtful	Inadequate	NA
	van de Rijt *et al.* (2019)	Adequate	NA	NA

Table 5.9: Methodological quality of orofacial pain measurement instruments studies.

5.4.4 Measurement properties rating (primary outcomes)

Ratings of the measurement properties' results of oral health measurement instruments are presented in Table 5.10. None of the results about construct validity were rated as sufficient. Regarding ratings the reliability results of the oral health measurement instruments, three of the instruments (i.e. THROAT, OHAT and OHSTNP) have shown to have an overall sufficient reliability, while the others were rated as either insufficient or indeterminate.

Ratings of the measurement properties' results of orofacial pain measurement instruments are presented in Table 5.11. The OPS-NVI is the only measurement instrument that has been rated as having sufficient construct validity. The reliability for all orofacial pain measurement instruments were rated overall as insufficient or indeterminate. Finally, the FACS was the only measurement instrument that demonstrated sufficient performance in responsiveness overall rating.

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Instrument name	Study	Construct validity			Reliability		
		Finding (range)	Rating	Overall rating	Finding (range)	Rating	Overall rating
BOHSE	Kayser-Jones *et al.* (1995)	–	–	**–**	CCR = 0.40–0.88	Inconsistent	**Indeterminate**
MPS	Henriksen (1999) (A)	–	–	**–**	K = 0.62	Insufficient	**Indeterminate**
	Henriksen (1999) (B)	–	–		K = 0.70–0.77	Sufficient	
THROAT	Dickinson *et al.* (2001)	-	–	**Insufficient**	K = 0.95–0.97	Sufficient	**Sufficient**
	Mckenzie (2015)	PCC= −0.02–0.41	Insufficient		–	–	
ROAG	Andersson *et al.* (2002)	–	–	**–**	K = 0.45–0.84	Insufficient	**Insufficient**
	Konradsen *et al.* (2014)	–	–		K = 0.09–0.33	Insufficient	
OHAT	Chalmers *et al.* (2005)	PCC= −0.10–1.00	Inconsistent	**Indeterminate**	ICC = 0.74–0.78	Sufficient	**Sufficient**
	Simpelaere *et al.* (2016)	–	–		ICC = 0.78–0.96	Sufficient	
	Klotz *et al.* (2020)	–	–		ICC = 0.77–0.91	Sufficient	
OHI	Liétard *et al.* (2013)	–	–	**–**	–	–	**–**
OAS	Yanagisawa *et al.* (2017)	–	–	**–**	K = 0.49–0.90	Inconsistent	**Indeterminate**
OHSTNP	Tsukada *et al.* (2017)	–	–	**–**	SCC = 0.81–0.85	Sufficient	**Sufficient**

- CCR= Correlation Coefficient r, K= Kappa Statistic, ICC= Intraclass Correlation Coefficient, PCC= Pearson Correlation Coefficient, SCC= Spearman’s Rank-Order Correlation

Table 5.10: Ratings of measurement properties of oral health measurement instruments.

Instrument name	Study	Construct validity			Reliability			Responsiveness		
		Finding (range)	Rating	Overall rating	Finding (range)	Rating	Overall rating	Finding (range)	Rating	Overall rating
FACS	Hsu *et al.* (2007)	PCC= -0.24 - 0.31	Insufficient	**Insufficient**	–	–	**–**	100% in accordance with hypothesis †	Sufficient	**Sufficient**
MOBID	Toxopeus *et al.* (2016)	–	–	**–**	K = 0.05–0.74	Insufficient	**Insufficient**	–	–	**–**
OPS-NVI	De Vries *et al.* (2016)	–	–	**Sufficient**	ICC = 0.41–0.76	Inconsistent	**Indeterminate**	–	–	**–**
	Delwel *et al.* (2018a)	Sn = 0–100% Sp = 66–100%	Not rated ‡		%PA = 53–64 %NA = 88–96	Sufficient		–	–	
	van de Rijt *et al.* (2019)	AUC = 0.82–0.92 SSC = 0.63–0.93	Sufficient		-	-		–	–	

- AUC= Area Under the Curve, ICC= Intraclass Correlation Coefficient, K= Kappa Statistic, %NA= Percentage Negative Agreement, %PA= Percentage Positive Agreement, PCC= Pearson Correlation Coefficient, Sn= Sensitivity, Sp= Specificity

† Clinically meaningful change in patients' scores was demonstrated before and after introducing painful interventions.

‡ Sensitivity and specificity were not rated because neither the research team nor the review team has defined a hypothesis in advance about their sufficient criteria.

Table 5.11: Ratings of measurement properties of orofacial pain measurement instruments.

5.4.5 Level of evidence (primary outcomes)

The quality of the evidence on the measurement properties' overall ratings (i.e. sufficient or insufficient) of the included oral health and orofacial pain measurement instruments is presented from Table 5.12 to Table 5.16. The quality of the evidence on the measurement properties showing indeterminate overall ratings was not undertaken or presented (e.g. reliability for BOHSE). In general, most of the evidence was evaluated as low or very low. The only exception among oral health measurement instruments was about the evidence on the reliability of the OHAT, which has been evaluated as high. In addition, evidence about the construct validity of the OPS-NVI has been evaluated as moderate.

Instrument name	Risk of bias	Inconsistency	Imprecision	Indirectness	Level of evidence
BOHSE	–	–	–	–	–
MPS	–	–	–	–	–
THROAT	Serious	No	Very serious	No	Very low
ROAG	–	–	–	–	–
OHAT	–	–	–	–	–
OHI	–	–	–	–	–
OAS	–	–	–	–	–
OHSTNP	–	–	–	–	–

Table 5.12: Grading the quality of the evidence about the construct validity of oral health measurement instruments.

Instrument name	Risk of bias	Inconsistency	Imprecision	Indirectness	Level of evidence
BOHSE	–	–	–	–	–
MPS	–	–	–	–	–
THROAT	Serious	No	Serious	No	Low
ROAG	Serious	Serious	No	No	Low
OHAT	No	No	No	No	High
OHI	–	–	–	–	–
OAS	–	–	–	–	–
OHSTNP	Very serious	No	Serious	No	Very low

Table 5.13: Grading the quality of the evidence about the reliability of oral health measurement instruments.

Instrument name	Risk of bias	Inconsistency	Imprecision	Indirectness	Level of evidence
FACS	Serious	No	Very serious	No	Very low
MOBID	–	–	–	–	–
OPS-NVI	Serious	No	No	No	Moderate

Table 5.14: Grading the quality of the evidence about the construct validity of orofacial pain measurement instruments.

Instrument name	Risk of bias	Inconsistency	Imprecision	Indirectness	Level of evidence
FACS	–	–	–	–	–
MOBID	Very serious	Serious	Very serious	No	Very low
OPS-NVI	–	–	–	–	–

Table 5.15: Grading the quality of the evidence about the reliability of orofacial pain measurement instruments.

Instrument name	Risk of bias	Inconsistency	Imprecision	Indirectness	Level of evidence
FACS	Very serious	No	Very serious	No	Very low
MOBID	–	–	–	–	–
OPS-NVI	–	–	–	–	–

Table 5.16: Grading the quality of the evidence about the responsiveness of orofacial pain measurement instruments.

5.4.6 Best evidence synthesis (primary outcomes)

Best evidence synthesis for the findings about the oral health and orofacial pain measurement instruments are presented in Table 5.17 and Table 5.18, respectively. OHAT showed the best performance among oral health measurement instruments by demonstrating high evidence of sufficient reliability. On the other hand, OPS-NVI has shown the best performance among orofacial pain measurement instruments by demonstrating moderate evidence of sufficient construct validity.

Instrument name	Construct validity	Reliability
BOHSE	NAs	±
MPS	NAs	±
THROAT	?	+
ROAG	NAs	–
OHAT	±	+++
OHI	NAs	NAs
OAS	NAs	±
OHSTNP	NAs	?

+++ or –––: high evidence of sufficient or insufficient results, ++ or ––: moderate evidence of sufficient or insufficient results, + or –: low evidence of sufficient or insufficient results, ?: unknown due to evidence with very low quality, ±: unknown due to inconsistent results, NAs: Not Assessed

Table 5.17: Best evidence synthesis of oral health measurement instruments.

Instrument name	Construct validity	Reliability	Responsiveness
FACS	?	NAs	?
MOBID	NAs	?	NAs
OPS-NVI	++	±	NAs

+++ or –––: high evidence of sufficient or insufficient results, ++ or ––: moderate evidence of sufficient or insufficient results, + or –: low evidence of sufficient or insufficient results, ?: unknown due to evidence with very low quality, ±: unknown due to inconsistent results, NAs: Not Assessed

Table 5.18: Best evidence synthesis of orofacial pain measurement instruments.

5.4.7 Interpretability and feasibility outcomes (secondary outcomes)

The interpretability of the included measurement instruments was evaluated based on the distribution of the instruments' scores in the form of mean and standard deviation. Instruments' scores in this context mean the numerical values that obtained when these instruments used to assess oral health or orofacial pain in dependent adults. In addition to the scores' distribution, two studies that are related to the OPS-NVI evaluated the presence and absences of floor and ceiling effects (i.e. these effects occur when 15% or more of the participants achieve the lowest or highest possible score), which could give more insight into the interpretability of this instrument. Findings about the interpretability of oral health and orofacial pain measurement instruments are presented in Table 5.19 and Table 5.20, respectively.

The feasibility of using the included measurement instruments was evaluated based on the three main factors, which are the time required to complete the measurements using these instruments, the training provided before using the instruments and the tools required for undertaking the measurements. Findings about the feasibility of oral health and orofacial pain measurement instruments are presented in Table 5.21 and Table 5.22, respectively. In general, the time required to complete the measurement was often less than 10 minutes. In addition, most of the instruments required simple or no tools to undertake measurements. However, the training provided to the participants before using the instruments varied widely because some of the studies provided up to four hours' training, while others provided minimal or no training at all.

Instrument name	Study	Scores distribution Mean (standard deviation)
BOHSE	Kayser-Jones *et al.* (1995)	4.29 (2.87) out of 20
MPS	Henriksen (1999)	4.48 out of 8
THROAT	Dickinson *et al.* (2001)	–
	Mckenzie (2015)	–
ROAG	Andersson *et al.* (2002)	10.16 (3.63) out of 24
	Konradsen *et al.* (2014)	–
OHAT	Chalmers *et al.* (2005)	2.54 out of 16
	Simpelaere *et al.* (2016)	–
	Klotz *et al.* (2020)	6.70 (2.80) out of 16
OHI	Liétard *et al.* (2013)	1.40 out of 8
OAS	Yanagisawa *et al.* (2017)	–
OHSTNP	Tsukada *et al.* (2017)	–

Table 5.19: Findings about interpretability of oral health measurement instruments.

Instrument name	Study	Scores distribution Mean (standard deviation)	Floor and ceiling effect
FACS	Hsu *et al.* (2007)	28.80 (9.60) †	–
MOBID	Toxopeus *et al.* (2016)	–	–
OPS-NVI	De Vries *et al.* (2016)	–	One item showed floor effect Nine items showed ceiling effect
	Delwel *et al.* (2018a)	–	14 items showed floor effect One item showed ceiling effect
	van de Rijt *et al.* (2019)	–	–

† Theoretically, the FACS does not have a maximum score.

Table 5.20: Findings about interpretability of orofacial pain measurement instruments.

Instrument name	Study	Training provided	Required tools	Completion time (minutes)
BOHSE	Kayser-Jones *et al.* (1995)	Two 2-hour training sessions about: • How to examine and evaluate oral health status • Overview of oral anatomy and oral and dental diseases • The instrument was reviewed with participants • Participants did examination under the research team supervision	Tongue blade, hand-held light, gauze square and disposable gloves	Range = 5.0–20.0 Mean = 7.4
MPS	Henriksen (1999)	• A pictorial manual containing 25 colour photographs was studied by the participants. • The instrument was reviewed and explained to the participants • Participants did some examinations from one to two hours under the research team supervision as part of the training	Headlight or hand-held light and two dental mirrors.	Range = 2.0–4.0
THROAT	Dickinson *et al.* (2001)	NR	Hand-held light and gloves	NR
	Mckenzie (2015)	• Online training package including an explanation about mouth anatomy and the THROAT score assessment tool • The instrument was reviewed with the participants • Participants did some examinations under the research team supervision as part of the training	NR	Range = 1.0–5.0 Mean = 2.1
ROAG	Andersson *et al.* (2002)	3-hour training sessions consisting of: • A lecture on oral health problems • Explanation about the ROAG	Hand-held light and dental mirrors	NR
	Konradsen *et al.* (2014)	A visual guide consisting of dental and oral pictures representing oral anatomy and oral and dental diseases was studied by the participants	Hand-held light and dental mirrors	NR

Instrument name	**Study**	**Training provided**	**Required tools**	**Completion time (minutes)**
OHAT	Chalmers *et al.* (2005)	A 3-hour training programme was completed with the participants in accordance with the BOHSE instrument training	Gloves	Range = 1.0–30.0 Mean = 7.8
	Simpelaere *et al.* (2016)	A 3-hour training programme was completed with the participants in accordance with the BOHSE instrument training	Gloves	Range = 0.4–6.2 Mean = 2.5
	Klotz *et al.* (2020)	The half-hour training consisted of explanation about the OHAT that included a demonstration with example images of different dental problems related to the answer categories of the OHAT	Hand-held light and gloves	NR
OHI	Liétard *et al.* (2013)	The participants were trained by the research team in the use of the OHI	NR	NR
OAS	Yanagisawa *et al.* (2017)	The participants were trained by the research team in the use of the OAS	NR	NR
OHSTNP	Tsukada *et al.* (2017)	OHSTNP was used without any training	Hand-held light, tongue blades and dental mirrors	Range = 1.9–3.1 Mean = 2.6

Table 5.21: Findings about feasibility of oral health measurement instruments.

Instrument name	Study	Training provided	Required tools	Completion time (minutes)
FACS	Hsu *et al.* (2007)	The participant is certified FACS coders	NR	NR
MOBID	Toxopeus *et al.* (2016)	NR	NR	NR
OPS-NVI	De Vries *et al.* (2016)	Standard instructions of the OPS-NVI were given to the participants	NR	NR
	Delwel *et al.* (2018a)	Standard instructions of the OPS-NVI were given to the participants	NR	NR
	van de Rijt *et al.* (2019)	NR	NR	Mean = 12

Table 5.22: Findings about feasibility of orofacial pain measurement instruments.

5.5 Discussion

This systematic review identified eight oral health and three orofacial pain measurement instruments that have been developed for use on different populations of dependent adults. In addition, the findings pertaining to these instruments' measurement properties, feasibility and interpretability have been synthesised to appraise the performances of these instruments. In the discussion section, the findings related to these instruments' performances have been matched and contrasted with the wider scientific literature to scientifically explain the variations in the performances among these instruments. In addition, this discussion sought to identify and highlight any potential gaps in the literature concerning the measurement properties, feasibility and interpretability of these measurement instruments. Lastly, the strengths and limitations of this systematic review were described and discussed.

5.5.1 Validity and responsiveness discussion

Validity is one of the domains in the psychometric field that can be defined as the degree in which a measurement instrument is truly measuring the construct that it is purported to measure (Bannigan and Watson, 2009; Mokkink *et al.*, 2010c). For health-related measurement instruments, there are three main validity-related measurement properties: content validity, criterion validity and construct validity (Mokkink *et al.*, 2010c). Despite responsiveness as a measurement property having been classified into a distinct quality domain by the COSMIN panel (Mokkink *et al.*, 2010c), findings of responsiveness in this systematic review were discussed alongside the validity findings. This is mainly because responsiveness is usually considered an aspect of both criterion validity and construct validity (i.e. in a longitudinal context) (De Vet *et al.*, 2011, p. 203). In fact, the only reason for classifying responsiveness into a distinct quality domain by the COSMIN panel was to emphasise the differences between the validity of a single score and the validity of the change score (Mokkink *et al.*, 2010c). In addition, as the approaches used to assess the responsiveness are often similar to those used for the assessment of validity (De Vet *et al.*, 2011, p. 202), this was another reason to discuss the findings of these properties together.

Content validity is one of the validity-related measurement properties that reflect how the content of a measurement instrument is a true representation of the construct being measured (Mokkink *et al.*, 2010c; Magasi *et al.*, 2012). While only a limited number of the included studies in this review have reported evaluating the content validity of their measurement instruments (Kayser-Jones *et al.*, 1995; Dickinson *et al.*, 2001; Chalmers *et al.*, 2005; Yanagisawa *et al.*, 2017), the outcomes of their evaluations were not incorporated into this systematic review synthesis. This is mainly because these studies evaluated the content validity of their measurement instruments by experts who were part of the development teams, and therefore, can be presumed to have a biased view toward their instruments. In addition, neither the method used to evaluate the content validity in these studies, nor the outcomes of the evaluations were reported fully or explicitly. It is widely accepted that to undertake a sound evaluation of a measurement instrument's content validity, a qualitative study utilising the cognitive interviews approach is needed to be conducted with independent group of experts regarding three main criteria (i.e. relevance, comprehensive and comprehensibility) concerning the measurement instrument (Brod *et al.*, 2009; Rothman *et al.*, 2009; Patrick *et al.*, 2011a; Patrick *et al.*, 2011b).

Nonetheless, the content validity of any measurement instrument can be indirectly evaluated by appraising the method used to develop the instrument (Magasi *et al.*, 2012). This is because the development procedure usually is the first step to support the content validity of measurement instruments (Magasi *et al.*, 2012). Thus, although most of the included studies in this systematic review were not completely transparent nor adequately thorough while reporting the methods that have been used to develop their instruments, appraising what has been reported might provide some indications about the content validity of the identified instruments. There were two major flaws in the development procedure in all included studies, which may have subsequently adversely affected the content validity of their measurement instruments. First, none of the included studies have referred to a conceptual model of oral health or orofacial pain for use as a theoretical base during the development of the instruments. In addition, all studies lacked inputs from the dependent adults during the instruments' development. It is important to capture the lived experience of dependent adults within the development of instruments especially if the measurement instrument under development is to inform person-centred care (Vogt *et al.*, 2004). Aside from appraising the development procedure, the instruments' items could also provide further insights into their content validity (Terwee *et al.*, 2018). For both oral health and orofacial pain measurement instruments, a trend of more comprehensive instruments that were being published over time was noticed (Table 5.6 and Table 5.7), and this may indicate that the more recently an instrument was published, the stronger the content validity. However, it must be noted that important domains of oral health, such as pain and noticeability, still were not adequately represented or measured in the oral health measurement instruments (Table 5.6).

Criterion validity and responsiveness are two of the most important measurement proprieties, which can be defined as the degree in which a measurement instrument is a true reflection of a gold standard in a single-point or in longitudinal context (Kimberlin and Winterstein, 2008; Mokkink *et al.*, 2010c). Only Mckenzie (2015) and Delwel *et al.* (2018a) have reported evaluating the criterion validity of the THROAT and the OPS-NVI, respectively. However, during the data analysis in this systematic review, these evaluations were considered as evaluations of the construct validity. This is because the measurement instruments used for the validation process in these studies did not fulfil the gold standard criteria. A gold standard in the context of this systematic review was defined as a measurement instrument that has been validated and accepted by the experts to be an ideal instrument that its scores precisely representing the oral health or orofacial pain in dependent adults (Bannigan and Watson, 2009; De Vet *et al.*, 2011, p. 161).

Construct validity and responsiveness are measurement properties that are about the degree in which the scores of a measurement instrument (i.e. in a single point or in a longitudinal context) are in accordance with a hypothesis that has been formulated in relation to the construct being measured (Strauss and Smith, 2009; Mokkink *et al.*, 2010c). In many cases a hypothesis can be formulated to be about the expected change in the scores after an intervention (Bannigan and Watson, 2009). Hypotheses can also be about the expected difference in scores between two relevant subgroups or about the expected correlation between the scores of the measurement instrument to another measurement instrument (Bannigan and Watson, 2009). The construct validity and responsiveness for many measurement instruments that were included in this review were evaluated and tested (Table 5.10 and Table 5.11). However, only the OPS-NVI demonstrated evidence of sufficient construct validity (Table 5.18). The final conclusions about the construct validity (i.e. of THROAT and FACS) and responsiveness (i.e. of FACS) were not established (Table 5.17 and Table 5.18). This was due to the very low quality of evidence that supported the findings of the validity and the responsiveness of these measurement instruments. This very low quality of evidence could be attributed to several factors. For example, as the hypotheses in all these studies were generic and were not developed according to existing theories and relevant data pertaining to oral health and orofacial pain in dependent adults, they may not correctly reflect the true magnitude and direction of correlation or change in scores. In addition, these studies did not establish their hypotheses in advance prior to data calculation, which could have led to potential biases during their analysis. Furthermore, the sample size in these studies was too small (Table 5.2 and Table 5.3).

Structural validity is another aspect of the construct validity, which reflects the agreement between the dimensionality of a measurement instrument with the dimensionality of the construct of interest (Mokkink *et al.*, 2010c). The assessment of structural validity through the construct approaches is only relevant for the identified orofacial pain measurement instruments because they are the only instruments developed based on reflective models (i.e. instruments that measure the consequences resulting from changes in the construct) (Reichenheim *et al.*, 2014). However, none of these instruments' structural validity has been assessed. On the other hand, the structural validity of measurement instruments developed based on formative models such as oral health instruments (i.e. instruments that measure the factors that cause change to the construct) are assessed during the content validity evaluation (De Vet *et al.*, 2011, p. 70). Thus, as the content validity of the identified oral health measurement instruments were not properly evaluated, evidence about their structural validity is still lacking. Establishing evidence about the structural validity of the identified instruments is crucial because it would enhance the formulation of other robust hypotheses during the construct validity evaluation (Reichenheim *et al.*, 2014).

The last aspect of construct validity is the cross-cultural validity, an aspect that has not been assessed for any of the included measurement instruments in this systematic review. Cross-cultural validity can be defined as the degree to which the performance of a measurement instrument that has been adapted into a new language or cultural situation is similar to the original instrument (Mokkink *et al.*, 2010c). Thus, due to almost all the included measurement instruments in this review being tested on a narrowly defined population of dependent adults, the evaluation of this measurement property is likely to be required before instruments are used in another population of dependent adults (Beckstead *et al.*, 2008; Prince, 2008).

5.5.2 Reliability discussion

Reliability is a domain in the psychometric field that is concerned with the consistency of measurement instruments when measuring unchanged construct under different conditions (Bialocerkowski and Bragge, 2008). There are three measurement properties that can explore and test the reliability of measurement instruments, namely reliability, measurement error and internal consistency (Mokkink *et al.*, 2010c). Among these three properties, reliability was the only measurement property that has been evaluated for the measurement instruments in this systematic review. Only the OHAT and the THROAT have been shown to have sufficient reliability, while other instruments have been demonstrated to have insufficient (i.e. ROAG) or inconsistent reliability (i.e. BOHSE, MPS, OAS and OPS-NVI) (Table 5.17 and Table 5.18). Reliability as a measurement property is evaluated by exploring the sources of variations in the observed measurements (Kimberlin and Winterstein, 2008). These variations in the observed measurements can occur due to true differences in the construct that is being measured or due to measurement errors (i.e. systematic or random errors) (Bialocerkowski and Bragge, 2008). Thus, a measurement instrument would not be considered reliable if the variations in its observed measurements are substantially attributed to measurement errors, as its measurements would be significantly inconsistent for an unchanged construct (Bialocerkowski and Bragge, 2008). Most of the statistical parameters that assess reliability aim to find the ratio of variance due to true differences in the construct being measured to the variance due to the true differences and to the variance due to measurement errors (i.e. this ratio is presented in the formula below) (De Vet *et al.*, 2011, p. 101).

$$Reliability = \frac{\sigma^2_{true\ differences}}{\sigma^2_{true\ differences} + \sigma^2_{error}}$$

Based on the reliability formula, there are two possible sources that can be responsible for the insufficient and inconsistent reliability of the measurement instruments in this systematic review. First, the poor reliability in the performance of these instruments could be attributed to a possibly large variance in their measurements due to the measurement error. While the values of measurement error were not reported for any of these instruments, there are indications supporting this explanation. The large variance due to the measurement error could occur when the participants who have undertaken these measurements do not have the adequate knowledge and skills to produce consistent measurements (i.e. among themselves and with others) (Bialocerkowski and Bragge, 2008). In fact, most of the measurements (i.e. obtained with the instruments with poor reliability) were undertaken by nursing staff (i.e. BOHSE and ROAG) and health care workers (i.e. MPS and OAS) (Table 5.4), who have been suggested to have insufficient knowledge and skills about dentistry or oral health (Reis *et al.*, 2011; Horne *et al.*, 2015).

This may suggest that in order to improve the reliability of these instruments, more training and calibration for the participants are needed before using them (Haresaku *et al.*, 2018; Haresaku *et al.*, 2020). The reliability of the OHAT and the OAS has been shown to significantly improve after training has been provided for participants with no dental background (Yanagisawa *et al.*, 2017; Klotz *et al.*, 2020). In addition, the training that was provided for the nursing staff and health care workers in the studies that have shown to have sufficient reliability seems to be more comprehensive and better than most of the studies that did not show a similar reliability in performance (Table 5.21).

However, extensive training may not be possible from a logistical perspective, especially if these measurement instruments to be implemented and used national wide (Shadadi *et al.*, 2018). Thus, developing an instrument that is simple and can meet the caregivers' level of oral health knowledge and skills could be an alternative approach that may establish sufficient reliability without the need for prior training. This approach is supported by the findings from the OHSTNP reliability study, which has succeeded in achieving an acceptable level of reliability without providing any training for their participants (Table 5.10) (Tsukada *et al.*, 2017).

It must be noted that the variations in the measurements may be incorrectly attributed to measurement errors, while in fact, these variations represent an actual change in the construct that is being measured. This can occur when the time between the measurements are relatively too long, and thus leads to a high chance for the measured construct to change between the different measurements (De Vet *et al.*, 2011, p. 125). This might have occurred in some of the included studies in this systematic review. As it is usually advisable to leave a two-week gap when assessing the intra-rater reliability, the constructs of oral health and orofacial pain could significantly change during this time period and thereby compromise the reliability of the instruments (Loe *et al.*, 1965; Kimberlin and Winterstein, 2008; Gibney *et al.*, 2017). In fact, this reason was suggested by Henriksen (1999) and Konradsen *et al.* (2014) in order to explain the insufficient reliability of the MPS and the ROAG, respectively.

The second source for the poor reliability of some measurement instruments in this systematic review could be due to the high homogeneity (i.e. in regard to the status of oral health and orofacial pain) among the samples of dependent adults within the included studies (Lakes, 2013). As the reliability is a ratio of the variance due to true differences in comparison to the variance due to measurement error, a small variation due to measurement error can significantly compromise the result of reliability if the sample is highly homogeneous (i.e. variance due to true changes is relatively small). Homogeneous samples could occur in studies when there are biases in the selection of the participants (Pike and Hudson, 1998). For example, Yanagisawa *et al.* (2017) utilised a self-selecting sampling method, which may have resulted in including dependent adults who have the highest interest in oral health among their sampling frame, which may explain why the OAS has failed to demonstrate sufficient reliability. However, even when the samples are highly heterogeneous, the variance stemming from true difference could be relatively small if the instrument is not adequately sensitive when measuring the construct of interest (De Vet *et al.*, 2011, p. 96). For example, Kayser-Jones *et al.* (1995) purposively selected patients with severe cognitive impairment in order to increase the heterogeneity among their sample. However, they still failed to demonstrate a sufficient level of reliability for the BOHSE (Table 5.10), because the BOHSE might not be sensitive enough to discriminate between the participants with different levels of oral health status. This could be supported by the reported mean and standard deviation of the BOHSE scores, which have placed most participants on the healthy side of the BOHSE scale (Table 5.19).

Although the reliability of the OHSTNP and the MOBID have been evaluated, final conclusions could not be drawn, because the level of evidence quality was very low for these two instruments (Table 5.13 and Table 5.15). This very low level of evidence was attributed to the small sample size in both studies (Toxopeus *et al.*, 2016; Tsukada *et al.*, 2017). In addition, both studies suffered from a number of methodological flaws that increased their risk of biases. For example, the reliability of the OHSTNP was evaluated using inappropriate statistical parameter (Tsukada *et al.*, 2017). In addition, Toxopeus *et al.* (2016) collected the data from 12 observers, and then only used the data from the best three observers to evaluate the reliability, which may have resulted in overestimating the reliability of the MOBID.

Measurement error is the second measurement property that can be used to assess the reliability domain (Mokkink *et al.*, 2010c). In general terms, measurement error is evaluated by comparing the standard error of the measurement with the instrument's minimally important change (i.e. change considered by clinicians and patients to be important) (Copay *et al.*, 2007; De Vet *et al.*, 2011, p. 122). A measurement error is considered to be acceptable when the standard error of the measurement is smaller than the minimally important change (Terwee *et al.*, 2007). This is because in this case, the instrument would be consistent when distinguishing between the different levels of the measured construct without being affected by its measurement error (Terwee *et al.*, 2007). However, none of the included studies in this systematic review evaluated the measurement error of their measurement instruments. As evaluating the measurement error is not affected by the homogeneity of the included sample (Bialocerkowski and Bragge, 2008), this evaluation can be particularly useful when assessing the reliability of these instrument if recruiting a heterogeneous sample is not possible. For example, recruiting adults with extreme case of dependency may not be possible due to difficulty in receiving their consent for participation, which may adversely affect the heterogeneity of the sample (Patel *et al.*, 2003; Kadam *et al.*, 2016).

Internal consistency is the last measurement property that is used to assess the reliability domain (Mokkink *et al.*, 2010c). It is unique because it assesses the consistency of different items in a multi-item measurement instrument when measuring the same construct (Terwee *et al.*, 2007). Internal consistency as a measurement property is only relevant for measurement instruments that are based on a reflective model such as orofacial pain measurement instruments, because the items of these instruments measure the consequences of orofacial pain, and as such, all these items are theoretically related to each other (De Vet *et al.*, 2011, p. 137). However, internal consistency was not evaluated for any of these measurement instruments. Evaluating the internal consistency for these instruments would ensure that a sufficient number of items were included to capture the construct of orofacial pain reliably (Salkind, 2010). In addition, this evaluation may help in improving the feasibility of these instruments by excluding redundant items that are measuring the exact same aspects of orofacial pain (De Vet *et al.*, 2011, p. 81).

5.5.3 Interpretability and feasibility discussion

Although none of the included studies in this systematic review has been specifically undertaken to evaluate interpretability or feasibility of their measurement instruments, some of the reported data from the included studies can be used to indirectly assess these two properties. Interpretability can be defined as the ability to assign a clinical meaning to a quantitative score that was obtained from a measurement instrument (Mokkink *et al.*, 2010c). Interpretability of the included measurement instruments in this review was evaluated based on the distribution of their scores (Table 5.19 and Table 5.20). Most of the standard deviations of the included measurement instruments' scores were relatively small, which may indicate that a small change in a score could reflect a substantial change in the construct that is being measured. However, because the characteristics of the samples in the included studies were usually not extensively described, it would be extremely difficult to distinguish if the small standard deviations reflect interpretability characteristics of the measurement instruments or only representing homogeneity of the samples in the included studies (De Vet *et al.*, 2011, p. 273). The interpretability of the OPS-NVI was assessed by evaluating floor and ceiling effects. However, the two studies that assessed these effects were not consistent, which may be attributed to the differences between their samples (De Vries *et al.*, 2016; Delwel *et al.*, 2018a). Nevertheless, there are many other aspects of interpretability that were not assessed for the included measurement instruments (e.g. smallest detectable change, minimal important change and response shift), and thus more studies providing data on the performance of the instruments are still needed.

Feasibility in the context of this systematic review refers to the degree in which a measurement instrument is easily applicable in a specific setting (Prinsen *et al.*, 2018). Data about the required training, required tools and the required time to undertake a measurement were used in this review to assess the feasibility of the included measurement instruments (Table 5.21 and Table 5.22). While several instruments in this systematic review required minimal or no training at all (i.e. OHSTNP), others required an extensive training priori to their use (i.e. BOHES, ROAG and OHAT), which might have significantly compromised their feasibility (Shadadi *et al.*, 2018). In addition, several studies suggested that dental mirrors are needed when using their measurement instruments (i.e. MPS, ROAG, OHSTNP), which may not be available in many settings such as care homes, and thus reduced these instruments feasibility (Göstemeyer *et al.*, 2019). Lastly, some of the included instruments in this systematic review required an extended time to be completed (Table 5.22), and thus they may not be feasible to be used routinely for oral care planning (Göstemeyer *et al.*, 2019). An example of these instruments is the OPS-NVI, which consist of 64 items and it takes 12 minutes to be completed (Table 5.22). However, because many other aspects of feasibility such as financial cost for these measurement instruments were not assessed, more feasibility studies are still needed.

5.5.4 Strengths and limitations

This systematic review, to the research team's knowledge, is the first study that aimed to systematically and comprehensively identify oral health and orofacial pain measurement instruments for dependent adults, as well as appraising their measurement properties, feasibility and interpretability. To achieve robust findings in this systematic review, several steps were undertaken to ensure the method's strength. First, the protocol of this study that describes the objectives and methods was developed and published before conducting the study to reduce *post hoc* biases. In addition, the methods used to search for the primary studies in this review were comprehensive, and therefore increased the chance of including all eligible studies. Furthermore, all the steps in this systematic review were undertaken by two independent reviewers, which aimed to minimise reviewer-related biases during the steps of studies selection, quality assessment, data extraction and data synthesis. Finally, this review was conducted according to the COSMIN methodology for systematic review, which has been successfully and widely used in the last decade and holds strong evidence to support its validity (Prinsen *et al.*, 2018).

Nevertheless, there are a few limitations in this systematic review that may have impact upon its internal and external validity. There are potential biases in this review that could be attributed to three major sources. First, due to the fact that all the included measurement instruments in this review were developed and tested on dependent elderly who are living in hospitals or care homes, it might not be appropriate to generalise the findings and conclusions of this systematic review beyond the tested populations. Indeed, this especially holds true for the conclusions about the orofacial pain measurement instruments, because all of these instruments had been specifically developed for patients with dementia. The second potential source for biases is the widespread case of methodological flaws among the included studies. This has limited the possibility to appraise the performances of many of the included measurement instruments, as the final evaluations of these instruments were unknown due to the very low quality of evidence. Moreover, due to the reasons to feasibility, the search in this systematic review was restricted to the English language, which would lead to the introduction of language-related biases. Including relevant studies that were published in other languages might of allow for the identification of more oral health and orofacial pain measurement instruments. In addition, including non-English studies may also improve the quality of the evidence about measurement properties for the included measurement instruments, and thus allow establishing more robust conclusions. Lastly, because there is no registration of studies of measurement properties, interpretability and feasibility (as there is for randomised clinical trials) (De Vet *et al.*, 2011, p. 281), it was not possible to assess the impact of publication bias on the results of this systematic review.

5.6 Conclusion

This systematic review revealed that there are eight oral health and three orofacial pain measurement instruments for dependent adults. However, none of these measurement instruments were shown to have been adequately and comprehensively tested to establish strong evidence in relation to their measurement properties, feasibility and interpretability. Nevertheless, some of the included measurement instruments in this review demonstrated sufficient performances in reliability (i.e. OHAT and THROAT) and construct validity (i.e. OPS-NVI). Thus, these instruments have the potential for future use once other measurement properties, interpretability and feasibility have been sufficiently tested and evaluated.

Chapter 6. Investigation of Oral Health Assessment for Care Planning of Dependent Patients after Stroke—A Qualitative Study

6.1 Introduction

The quantitative systematic review in the last chapter identified several measurement instruments with evidence to support their use in assessing oral health in dependent adults. However, although these instruments were developed decades ago, they have never been widely adopted in daily clinical practice (Dickinson *et al.*, 2001; Chalmers *et al.*, 2005). This may be because developing health-related measurement instruments based on scientifically sound evidence is not a guarantee of their success during the implementation and application phase (Nilsen, 2015). In fact, according to a number of healthcare implementation theories, many factors other than the quality of evidence can determine implementation and application success (Moullin *et al.*, 2015). These factors can be related to the measurement instrument itself, the users (i.e. service providers), the receivers (i.e. dependent adults) and the application environment (Flottorp *et al.*, 2013; Atkins *et al.*, 2017).

The literature review in Chapter 2 did not identify any study that had investigated these factors in relation to the use of oral health measurement instruments for dependent adults. Thus, to develop an oral health measurement instrument that has the potential to be successfully implemented, these factors need to be identified and explored. Qualitative methods have been shown to be the best and most effective approach for this type of research enquiry, because of their ability to answer such exploratory questions (Fossey *et al.*, 2002).

Because there are numerous causes for dependency in adults that can have significantly different prognoses and outcomes, “dependent adults” is an umbrella term that can represent a highly heterogeneous population (Wilkin, 1987). Thus, it would be extremely difficult from a feasibility point of view to conduct a primary qualitative study that represents the whole population of dependent adults. Therefore, when studying a phenomenon about dependent adults, it might be more efficient at the outset to select a population subset that can adequately reflect the variability within the entire population.

Patients after stroke are a population that may represent the full spectrum of dependency in adults for several reasons. First, dependency after stroke could occur in patients due to physical or cognitive debilitation, or both (Ullberg *et al.*, 2015; Sennfalt *et al.*, 2018). In addition, although stroke patients tend to be older, they can also be relatively young (Lee *et al.*, 2011). Furthermore, dependency-related prognoses amongst patients after stroke are highly varied (Ullberg *et al.*, 2015; Sennfalt *et al.*, 2018). This is because depending on the severity of the stroke, some patients may gain their full independence in a short period of time, while others may become permanently dependent on others (Ullberg *et al.*, 2015; Sennfalt *et al.*, 2018). Lastly, dependent patients after a stroke may then live in a wide variety of settings, including hospitals, care homes and their community (Lee *et al.*, 2011).

Therefore, this study was conducted to explore how service providers perceive the oral health in post-stroke dependent patients and how it should be assessed as a means to understand this topic in relation to the larger population of dependent adults.

6.2 Aim

To explore and understand service providers' experiences and views about oral health in dependent patients (after a stroke), as well as implementation issues and potential barriers for measuring oral health in these patients.

6.3 Methods

6.3.1 Philosophical assumptions in qualitative research

It is essential to clearly define and describe the philosophical assumptions that underpin this study to justify the methods used and the interpretation of results. In general, the philosophical assumptions of the researchers in the qualitative field are based on their stances toward ontology and epistemology (Nicholls, 2009a).

Ontology in the context of qualitative research can be defined as the researcher's beliefs about the nature of social reality (Nicholls, 2009a). There are numerous positions adopted by qualitative researchers regarding ontology, and they can be arranged in a continuum between two extremes. On one end of the continuum, known as realism, researchers accept that social reality is independent of people's perceptions and beliefs. On the opposite end is idealism, which suggests that social reality is entirely dependent on individual perceptions and beliefs, and thus no reality exists independently of the human mind (Ritchie *et al.*, 2014). This study has adopted a more moderate position known as subtle realism, which accepts that reality exists independently and externally of individuals, but can only be comprehended through human minds and socially constructed meanings (Andrews, 2016).

Epistemology can be defined as the researcher's beliefs about the nature of knowledge and how knowledge of the social world can be acquired. It has been suggested that there are two approaches to acquiring this knowledge: inductive and deductive reasoning (Nicholls, 2009a). Inductive reasoning can be defined as an approach by which patterns and theories are established based on observations made (Nicholls, 2009a). Deductive reasoning, in contrast, starts with establishing a logic-driven hypothesis and propositions, which are later tested against the observations (Nicholls, 2009a). While this study has adopted the inductive reasoning approach, utilising "pure" inductive reasoning in analysing the data was not possible. This is because the PhD student has previously acquired knowledge on this topic from the literature review and the two systematic reviews, which would inevitably affect the data analysis process.

The other epistemological concern in qualitative research is the nature of the relationship between the researcher and the researched subject (Nicholls, 2009a). Qualitative researchers face two main opposing positions toward this epistemological issue: positivism and interpretivism (Ritchie *et al.*, 2014). Positivism can be defined as the belief that there is only one objective reality that is not affected by the researchers or the research process (Ritchie *et al.*, 2014), and interpretivism indicates a belief in multiple realities that can be affected by the researchers and the research process (Creswell, 2013). Interpretivism is the stance usually adopted in qualitative research (Nicholls, 2009a), including this study. This is because it is widely accepted that individuals in the social world represent different and unique cases and are affected by the process of being studied, and thus the researcher cannot be isolated from the phenomenon being studied (Creswell, 2013). Adopting this position allows the researchers to be transparent and considerate about their assumptions, biases and values, and thus, they can exercise deliberate effort to be as natural and non-judgmental in their approach as possible.

Another epistemological issue in qualitative research regards what it means to accept a specific claim to be accurate or "true" (Nicholls, 2009a). In quantitative research, it is widely accepted that there is an absolute match between the observations of the natural world and the independent reality of that world (Nicholls, 2009a). However, in the social world, it has been suggested that observations are only a consensual representation of the independent reality (Ritchie *et al.*, 2014). Known as the intersubjective or coherence theory of truth, it has been adopted in this study (Ritchie *et al.*, 2014).

6.3.2 Methodologies in qualitative research

Hammell (2006) defined qualitative research methodology as "a specific philosophical and ethical approach to developing knowledge; a theory of how research should, or ought, to proceed given the nature of the issue it seeks to address". Based on the different philosophical frameworks that underpin qualitative research, many qualitative methodologies have been described in the scientific literature (Thorne, 2000; Nicholls, 2009b). However, those most commonly used in the healthcare field are phenomenology, ethnography and grounded theory (Nicholls, 2009b). These methodologies are briefly described in the following paragraphs.

The phenomenological methodology has been strongly influenced by the philosophy of interpretivism that emphasises the uniqueness of individuals where each individual creates their own distinctive reality (Nicholls, 2009b). Thus, the phenomenological methodology aims to understand reality by gaining a detailed and in-depth understanding of an individual's lived experiences (Nicholls, 2009b). Traditionally, the phenomenological methodology sought to describe rather than explain without imposing any *a priori* hypothesis or preconceptions (Groenewald, 2004). However, this traditional view has been criticised more recently by humanist and feminist researchers who believe that it is impossible to conduct a study without having any preconceptions or biases (Groenewald, 2004). Thus, they stressed the importance of transparency in phenomenological studies regarding how the interpretations and meanings have evolved from the findings, as well as acknowledging that the researcher in this type of study is a subjective actor rather than a detached and impartial observer (Groenewald, 2004). Nonetheless, this methodology is most useful and effective when utilised to highlight people's subjective experiences and perceptions that can challenge structural and normative assumptions (Groenewald, 2004).

The foundations of ethnographic methodology can be traced back to anthropological studies conducted in the early 1900s to study small and rural societies (Reeves *et al.*, 2008). Currently, the ethnographic methodology is mainly concerned with exploring and understanding social interactions, behaviours, and perceptions that occur within a group of individuals (Reeves *et al.*, 2008). In the context of this methodology, the group of individuals is defined by their culture, which is not only determined by their ethnical bond but by any bond capable of grouping them together, such as a shared value, interest, disease or health condition (Nicholls, 2009b). The central aim of ethnographic studies is to understand how cultural practices, ideas and beliefs influence people in ascribing meanings to their lives (Nicholls, 2009b). Thus, they are usually undertaken by researchers who immerse themselves into the studied group and their setting to engage and develop a close relationship with that group, and hence establish a rich understanding of phenomenon under investigation (Reeves *et al.*, 2008).

The grounded theory methodology was first described by Glaser and Strauss (1967). Currently, there are several distinct grounded theory genres that represent an extension and development of the original methodology (Chun Tie *et al.*, 2019). The first is the traditional grounded theory, and it is associated with Barney Glaser (Chun Tie *et al.*, 2019). The Glaser genre focuses on establishing a conceptual theory that accounts for a pattern of behaviour relevant to the stakeholders (Chun Tie *et al.*, 2019). In contrast, Strauss, Corbin and Clarke founded the evolved grounded theory, which is heavily influenced by the symbolic interactionism theory (Chun Tie *et al.*, 2019). The latter suggests that meanings in our world are generated by the symbolic interactions between people (Chun Tie *et al.*, 2019). Lastly, the constructivist grounded theory developed by Kathy Charmaz focuses on how participants and researchers co-construct meaning in relation to the phenomenon being studied (Chun Tie *et al.*, 2019). In general, the grounded theory methodology is characterised as being more systematic, ordered and structured than the other methodologies, which may explain its widespread use by healthcare researchers (Nicholls, 2009b). Studies practicing this methodology are usually undertaken in multiple stages of collecting, refining and categorising data to establish a robust and reasoned theory that is grounded in (i.e. based on) the data (Kolb, 2012). This structural way of collecting and analysing data is known as the constant comparative method, which is incorrectly referred to by some researchers as grounded theory methodology (Chun Tie *et al.*, 2019).

When a research question does not fit neatly within the confines of a specific qualitative research methodology, adopting the “generic qualitative approach” might be more suitable (Cooper and Endacott, 2007). This approach permits deviation from the intent, rules or guidelines of the specific qualitative methodologies to better match the research purpose (Kahlke, 2014). Therefore, when utilising this approach, it is necessary to exhaustively describe the methods that have been used (Cooper and Endacott, 2007). It is equally important to thoroughly discuss other potential quality issues, such as reflexivity and establishing rigour (Cooper and Endacott, 2007). These detailed descriptions and discussion of the research framework are crucial to ensure the methodological validity and trustworthiness of studies utilising this approach (Cooper and Endacott, 2007). The generic qualitative approach is increasingly practiced in the healthcare research field (Kahlke, 2014), and it has been adopted in this study.

6.3.3 Ethical considerations

During the development of the study protocol, patients and the public were involved in designing the study methods via a meeting with the Stroke Patient and Carer Panel (PCP) group, a collaboration between the National Institute for Health Research Clinical Research Network North East and North Cumbria and the City Hospitals Sunderland NHS Foundations Trust. This group consists of stroke survivors, their family carers and service providers. The discussion in this meeting was about the general aim of the study, the recruitment and consent process (i.e. including feedback about the information sheet), data collection and data analysis (i.e. including feedback about the topic guide), and the dissemination strategy.

Notably, most of the PCP group members strongly related to the aim of this study because of their previous experiences. Minor modifications suggested during the meeting were adopted in the study protocol. For example, it was suggested to explain some of the technical and dental terms in the information sheet. In addition, a number of questions were suggested to be added to the topic guide (i.e. the document used during the interviews to outline the key issues and subtopics to be explored with the participants to answer the research question). Examples of these questions are what does oral health mean to service providers in general, do the services providers have an oral health measurement instruments in their settings, and if so do they use it and did they have previously trained to use it. Patient and public involvement is vital from the ethical perspective because it ensures that the study is relevant from the patient and public viewpoints (Gray-Burrows *et al.*, 2018). Thus, the study could potentially address the most important needs of the population, and study outcomes could have greatest number of beneficial impacts (Gray-Burrows *et al.*, 2018).

Generally, there was no anticipation of any material ethical issues in executing this study, as the study is based on the general view and perception of service providers regarding oral health and its assessment in patients after stroke. The study did not aim to investigate specific patient cases or to explore sensitive information, and there was no direct contact with patients. In addition, because sensitive issues were not discussed, the potential for distress was minimal.

A favourable ethical opinion was provided by the Faculty of Medical Sciences Ethics Committee at Newcastle University (FMS-EC 1609/6994/2018; Appendix G). In addition, the Health Research Authority (HRA) Approval was obtained to undertake this study with NHS staff on their premises (HRA: 248888; Appendix H). This study was funded by the PhD bench fees at the School of Dental Sciences—Newcastle University, which were provided by the Saudi Arabian Cultural Bureau in London.

6.3.4 Sampling

Many sampling strategies have been proposed in the literature describing how to select a subset from a population, in order to study it. Sampling strategies can generally be divided into probability and non-probability sampling (Marshall, 1996). Probability sampling strategies are often used in quantitative research and are done by randomly selecting members from a population in which each member in that population has a known probability for being selected (Marshall, 1996). While probability sampling is the best approach form a statistical point of view to generate a representative sample in quantitative research, it is not the best approach for qualitative studies (Marshall, 1996; Gentles *et al.*, 2015). This is because qualitative research often aims to gain a deep understanding of a specific phenomenon in a population rather than enumerating simple quantitative characteristics of that population (Suri, 2011). Thus, the selection of participants in qualitative studies should aim to incorporate the wide spectrum of features and characteristics of the sampled population by recruiting a wide range of individuals, even those with low prevalence characteristics who may not be easily recruited using probability sampling (Suri, 2011). In addition, sampling in qualitative studies should intentionally select participants with the richest experiences who could provide deeper insights and views into the topic of interest (Marshall, 1996; Suri, 2011). Thus, non-probability sampling is often utilised in qualitative research.

The non-probability sampling method used in this study is purposive (i.e. criterion-based) sampling utilising a maximum variation technique. This sampling strategy aims to identify and recruit participants with distinctive features and characteristics based on previously defined criteria, to generate a sample that is capable of adequately reflecting the true depth and breadth of the phenomenon under investigation (Palinkas *et al.*, 2015).

Nevertheless, principles of theoretical sampling have also been adopted in this study. Theoretical sampling has been developed as part of the grounded theory methodology (Glaser and Strauss, 1967). It aims to establish a data-based theory by jointly collecting, coding and analysing the data, in order to determine which data to be subsequently collected and from where (Coyne, 1997). The suggested benefit from utilising theoretical sampling method is that if data collection and analysis were done concurrently (i.e. as in this study), there is a substantial chance of identifying new avenues that could be investigated by recruiting new participants who are relevant to those dimensions (Gentles *et al.*, 2015). For example, in this study, it was revealed after the first couple of interviews in Salford that the Mouth Care Matters programme was recently adopted in the trust, and therefore, the dental professionals who are leading this programme were targeted for interviewing.

There were several pre-defined criteria that were used to define the purposive sampling strategy for this study: locations where the stroke services are provided, profession of healthcare provider, experience and gender (Table 6.1).

The participants were equally recruited from two NHS trusts in the north of England (i.e. Newcastle and Salford). The Salford Royal NHS Foundation Trust was selected as one of the research sites because it has been known to have a particular interest in oral health and care, demonstrated by the adoption of the Mouth Care Matters programme in its wards. In addition, the stroke wards, in particular, are led by a medical team who have undertaken several studies about oral health in post-stroke patients. Including two trusts with different levels of interest in oral health could help in increasing the variation in views and perspectives regarding the phenomenon under investigation.

Another sampling criterion was the profession and designation of the recruited service providers. Service providers were recruited if their roles and duties are relevant to stroke patients' oral health or oral care. Service providers were recruited from medical background (i.e. physicians, speech and language therapists [SLT] and nurses) and a dental background (i.e. dentists, hygienists and dental nurses). In addition, to maximise the variation among each profession, service providers were recruited from a wide range of designations. For example, the physician and dentist designations ranged from consultant to speciality trainee and the nurse designations ranged from ward manager (band 7) to support worker (band 2). In addition, nurses were recruited from acute and rehabilitation settings.

Service providers in this study were recruited if they had at least three months' experience with patients after stroke. In addition, to represent a wide range of views and perspectives, the service providers were purposively sampled from three strata based on the length of their experiences (i.e. < 5 years, 5 - 15 years, > 15 years). The differences in length of participant experience between the three strata were used because it was thought that more experience was expected to be gained in the early years of a career than in the later ones (Ericsson, 2008).

The last criterion considered in the sampling was the gender of the service providers. Even though the purposive sampling in this study aimed to provide a balanced representation, it was extremely difficult to recruit male participants from several professions (e.g. nurses and speech and language therapists). This may reflect the fact that these professions are overwhelmingly occupied by female professionals. Many previous qualitative studies undertaken within these professions were conducted with only female participates (Weeks and Fiske, 1994; Fiske and Zhang, 1999). Nevertheless, four male participants were recruited for this study, and they did not provide any unique views or perspectives that could be attributed to their gender.

Service providers were recruited for this study by working closely with gatekeepers in the two research sites to generate sampling frames of potential participants. This involved having meetings with the gatekeepers to discuss which of their staff may fulfil the inclusion criteria and represent good candidates for recruitment. The PhD student took part in this step to reduce possible gatekeepers' bias when generating the sampling frames and to ensure adequate diversity among the recruited participants. The potential participants who have been identified were approached and contacted by the PhD student. Then, they have been provided with a brief verbal description about the study and its aims, as well as a written participant information sheet (Appendix I). Each potential participant was left to reflect on the information issued in verbal and written format for as long as they deem necessary by them prior to making their decisions. Lastly, written informed consent was received from each recruited participant before undertaking the interview (Appendix J).

The sample size in this study was determined based on the concept of data saturation. Data saturation can be defined as the point when undertaking more interviews would not result in revealing new concepts or ideas (Gentles *et al.*, 2015). Thus, data were collected and analysed concurrently until data saturation was achieved.

Criteria	**Details**
Location	• Newcastle upon Tyne Hospitals NHS Foundation Trust • Salford Royal NHS Foundation Trust
Profession	• Medical background ○ Physician ○ Speech and language therapist (SLT) ○ Nurse • Dental background ○ Dentist ○ Hygienist ○ Dental therapist ○ Dental nurse
Experience	• Less than five years • Between five and 15 years • More than 15 years
Gender	• Male • Female

Table 6.1: Summary of the purposive sampling strategy in the qualitative study.

6.3.5 Data collection

To collect data for qualitative research, observation, focus groups and interviews are used (Barrett and Twycross, 2018). Researchers utilising the observational approach in qualitative studies usually immerse themselves to systematically record and explore the actions and interactions of the population within their natural settings (Barrett and Twycross, 2018). One of the main advantages of this approach is attributed to its ability to capture the true actions and behaviours of people that might not match their spoken views (Creswell, 2013). However, the risk of the Hawthorne effect on this type of data collection cannot be ignored because individuals usually modify their behaviours to improve their images when they are under observation (Ritchie *et al.*, 2014). In addition, researchers might be biased regarding what to observe and what to record (Ritchie *et al.*, 2014). Furthermore, this type of data collection usually requires the expenditure of extensive time and resources (Ritchie *et al.*, 2014).

Conducting focus groups is another data collection approach in qualitative research, in which a number of individuals discuss the phenomenon under investigation through the interaction between the participants and the focus group's facilitator (Barrett and Twycross, 2018). The main advantage of a focus group is that it provides an opportunity for the participants to build on each other's experiences and views, and thus may encourage them to freely exchange their perception and beliefs (Gill *et al.*, 2008). However, any focus group can be at risk of being dominated by one vociferous participant (Gill *et al.*, 2008). This can be particularly true in studies that are conducted with a range of health service providers where the professional hierarchy can affect the responses of some of the participants (Ritchie *et al.*, 2014). In addition, another limitation of focus group is that it is a difficult setting in which to explore individual cases in depth (Barrett and Twycross, 2018).

Interviewing is one of the most commonly used approaches to collect data in health-related qualitative research (Gill *et al.*, 2008). There are three main types of qualitative interviews: structured interviews, semi-structured interviews and in-depth interviews (Gill *et al.*, 2008). In structured interviews, all participants are asked a fixed set of questions established in advance (Creswell, 2013). Semi-structured interviews utilise a more flexible approach. In addition to the predefined questions, the interviewer can explore unique and unanticipated dimensions by diverging from the topic guide (Creswell, 2013). Lastly, in in-depth interviews, the interviewer begins with one or two previously defined broad questions, and subsequent questions are based on the participant responses (Creswell, 2013).

Semi-structured interviews were used in this study because they allow investigation of important topics based on the results of the literature review and two systematic reviews, in addition to investigating new and unique areas. The interviews were conducted with the help of a flexible and evolving topic guide, which was initially developed based on the literature and the two systematic reviews. In addition, its content validity was further supported by feedback from the supervisory team and the PCP group (see section 6.3.2). The topic guide employed open and non-leading questions and throughout the study, the topic guide was continuously refined based on the new data that have been collected and analysed. The final version of the topic guide is available in Appendix K.

All the interviews followed a standard operating procedure to enhance the consistency (Appendix L). At the beginning of the interviews, the interviewees were advised that the aim of the interview was not to critique their level of knowledge or their current practice but to capture their views, beliefs and perspectives about the phenomenon under investigation. It was made clear to them that their views and perspectives are crucial because they represent a unique component within the overall narrative. This was undertaken to encourage the participants to speak about their views and beliefs freely and with minimal concern.

In general, each interview could be divided into four major parts. The first part of the interview aimed to explore the experiences, roles and duties of the interviewee in relation to post-stroke patients. This intended to set them at ease as individuals tend to be comfortable speaking about their day-to-day practice (Ritchie *et al.*, 2014). In the second part of the interview, the interviewee was asked about their perceptions about oral health in patients after stroke. This includes asking the interviewee about their perceptions regarding the oral health status in post-stroke patients, factors that affect their oral health, and how oral health impacts the lives of patients after a stroke. Subsequently, the interview focused on exploring the interviewee's perceptions regarding the oral health assessment in post-stroke patients. This included questions about instrument features, potential assessment barriers and implementation strategies. In the final part of the interview, the interviewee was asked to read three oral health measurement instruments that have been previously used with patients after stroke to provide their opinions on the relevance, comprehensiveness and comprehensibility of these instruments (Appendix M). These measurement instruments were used as prompts during the interview to further investigate the interviewee's views and to contrast their views with those that have been previously published.

The semi-structured interviews were conducted by the PhD student who underwent substantial training in interview skills and analysis. It must be noted that none of the interviewees had a personal or professional relationship with the interviewer. All the interviews were undertaken face-to-face on NHS premises.

All the interviews were digitally recorded using a Philips DPM7000 voice recorder. Then, each digital file was anonymised using a study number. The anonymised recordings were transcribed verbatim by a professional transcription company, and the generated transcripts were crosschecked for accuracy against the original recordings by the PhD student. Each participant who completed the interview was recompensed for their time with a £20 gift card.

6.3.6 Data analysis

Data in this study were analysed in multiple steps with the assistance of NVivo 12 ® software. The constant comparative method was utilised during the analysis. Thus, data collection and analysis were performed concurrently to explore any emerging paths of inquiry through the refinement of the topic guide questions and hypothesising about the phenomenon under investigation (Grove, 1988). In addition, collecting and analysing data concurrently helps to examine for, and identify, any negative cases and responses that contradict the prevailing views to better understand the emerging themes and concepts (Grove, 1988).

The first step in data analysis was familiarisation, which began by listening to the original professionally transcribed records verbatim while checking transcription accuracy. Also, in this step, the interview transcripts were read and reread, which was accompanied by recording initial ideas and comments about the interviews.

The coding process was then undertaken following the method described by Corbin and Strauss (2014). The first step in the coding process was open coding, initially labelling, categorising and organising the qualitative data. The names of codes were established based on the terms used by participants or by the research team. Open coding in this study was a line-by-line coding to allow the generation of adequate numbers of codes that could later be used to robustly establish the overriding themes.

Axial coding was the second step in the coding process. It explored the relationships between the codes that were established during the open coding step. This type of coding is done by utilising deductive and inductive reasoning. The last step was selective coding, which is more abstract than the previous steps. It was completed by identifying a central theme within the study findings and exploring the relationships between this theme and other themes to eventually build a "picture of reality" (Corbin and Strauss, 2014).

The findings and interpretations in this study were independently cross-checked by three supervisors (Prof Giles McCracken, Prof Justin Durham and Dr Rebecca Wassall) at different stages of data collection and analysis to minimise potential biases and enhance the rigour of the study.

6.4 Results

Data were collected until data saturation was achieved upon completion of the 30th interview. This number of interviews is consistent with similar qualitative studies in the dental field (Lindqvist *et al.*, 2013; De Visschere *et al.*, 2015). Detailed characteristics of the 30 interviewed participants are presented in Table 6.2. The mean duration of the interviews was 40 minutes and ranged from 25 to 67 minutes.

This study investigated two distinctive topics using the perspectives of service providers: 1) oral health in dependent patients after admission for stroke and 2) assessment of oral health for those patients. Thus, the findings from this study were presented in two main sections accordingly. In addition, the data/results and discussion of each section were presented simultaneously to help the readers' comprehension, a routine practice in the qualitative research field (Mays and Pope, 1995). The first section presents and discusses service provider perceptions about the post-stroke patients' oral health status. The second section presents and discusses service provider perceptions about oral health assessment in post-stroke patient. The results discussed in both sections are supported by direct quotes from the participants, which are representative of the qualitative data. In some instances, these quotes have been clarified or contextualised by adding additional words in squared brackets, whilst ensuring that the original meaning was not changed or compromised. At the end of each quote, an acronym between parentheses was used to refer to participant profession, setting and identification number. For example, the acronym (Physician-N-P1) refers to the participant with an identification number (P1) who is a physician and works in the Newcastle upon Tyne Hospitals NHS Foundation Trust. The identification number in the acronym can be compared back to Table 6.2 for reference purposes.

Identification number	Years of experience	Profession	Gender	Location
P1	5 - 15 years	Physician (Consultant)	Male	Newcastle
P2	< 5 years	Dentist (Speciality trainee)	Male	Newcastle
P3	5 - 15 years	Dentist (Senior officer)	Female	Newcastle
P4	> 15 years	Physician (Consultant)	Female	Newcastle
P5	5 - 15 years	Speech and language therapist	Female	Newcastle
P6	5 - 15 years	Nurse (Rehabilitation)	Female	Newcastle
P7	< 5 years	Nurse (Rehabilitation)	Female	Newcastle
P8	5 - 15 years	Dental hygienist	Female	Newcastle
P9	< 5 years	Nurse (Rehabilitation)	Female	Newcastle
P10	< 5 years	Nurse (Acute)	Female	Newcastle
P11	5 - 15 years	Nurse (Acute)	Female	Newcastle
P12	> 15 years	Dental therapist	Female	Newcastle
P13	5 - 15 years	Nurse (Acute)	Female	Newcastle
P14	< 5 years	Speech and language therapist	Female	Newcastle
P15	< 5 years	Dentist (Speciality trainee)	Female	Newcastle
P16	< 5 years	Nurse (Acute)	Female	Salford
P17	> 15 years	Nurse (Acute)	Female	Salford
P18	5 - 15 years	Nurse (Acute)	Female	Salford
P19	5 - 15 years	Speech and language therapist	Female	Salford
P20	< 5 years	Speech and language therapist	Female	Salford
P21	5 - 15 years	Speech and language therapist	Female	Salford
P22	> 15 years	Dentist (Specialist)	Female	Salford
P23	5 - 15 years	Dentist (Senior officer)	Male	Salford
P24	> 15 years	Dental nurse	Female	Salford
P25	> 15 years	Dental nurse	Female	Salford
P26	< 5 years	Nurse (Rehabilitation)	Female	Salford
P27	5 - 15 years	Physician (Speciality trainee)	Female	Salford
P28	5 - 15 years	Physician (Consultant)	Female	Salford
P29	5 - 15 years	Nurse (Rehabilitation)	Male	Salford
P30	5 - 15 years	Nurse (Rehabilitation)	Female	Salford

Table 6.2: Characteristics of the qualitative study participants.

6.5 Data and Discussion Part 1: Service Providers Perceptions about Patients' Oral Health Status

The overwhelming majority of the participants in this study stated that patients experience numerous oral health problems after stroke for many different reasons. However, they also indicated that oral health status varies significantly among patients based on the severity of the stroke, as well as the baseline oral health status.

> *"I think it's quite a broad spectrum because obviously, you know, a patient that's kind of come in that perhaps has quite good oral health at baseline and then has had a small stroke, who can still be independent, then it's going to be a lot less of a problem. So, I think we do see quite a variety on the stroke ward, not everybody's at the end of having very poor oral hygiene"* (SLT-N-P15)

Participants in this study revealed a plethora of factors that can cause oral health deterioration in post-stroke patients. These factors would either directly or indirectly (i.e. by affecting the ability to perform or receive oral care) impact the oral health of patients after stroke. These factors have been classified in this synthesis according to their origins as patient-related, service provider-related or environment-related factors. The following results and discussion subsections present these factors as well as the overall impact of oral health deterioration on patients' lives after stroke, including aspects such as general health and quality of life.

6.5.1 Patient-related factors theme

There are many perceived causes for the deterioration of oral health in post-stroke patients that are related to the patients themselves and have been presented and discussed in this theme. These causes include difficulties in performing or receiving daily oral care. In addition, post-stroke neurological deficits and patients' general health, other contributing factors in compromising patients' oral health status, have been discussed in this theme.

Difficulties around undertaking oral care and their impact on oral health

Losing mobility and manual dexterity after stroke was reported by the participants to be one of the factors that can negatively impact a patient's ability to independently perform optimal oral care, and could subsequently lead to oral health deterioration in that patient.

> *"I guess depending on the severity of the stroke if that patient has got unilateral or even bilateral complete paralysis that might then affect their movement ability, their dexterity. They might not be able to get in to independently maintain their oral care. So, with that comes challenges of getting in and brushing the teeth, removing food debris or accumulations within the mouth"* (Dentist-N-P14)

This was viewed to be especially true for patients who are not supported by caregivers and thus are compelled to perform oral care independently. In addition, patients who lack access to oral care tools that could help them overcome the decline in their mobility and manual dexterity (e.g. electronic toothbrush) are at possibly an even greater risk of oral health deterioration.

It has been estimated in previous studies that up to 74% of stroke survivors can experience some form of physical disability that negatively affects their ability to independently perform different activities of daily life (Carmo *et al.*, 2015). It is clear from the large number of studies that have explored the topic of oral care in post-stroke patients that the researchers acknowledge the significant impact of stroke on patients' oral care (Ajwani *et al.*, 2017; Lyons *et al.*, 2018). However, none of these studies have specifically explored the specific effects of stroke on the patients' independent ability to perform oral care.

Another reason perceived by the participants for losing the ability to independently undertake optimal oral care after stroke is that some patients experience a deterioration in their cognitive status. This deterioration can affect their ability to recognise the existence of some parts of their mouth, and thus lead to neglect of those parts during the oral care process.

> *"They might have neglect on that side [of the mouth] but obviously not necessarily realise that they need to brush that side. They might brush one side, and it's not a visual problem or a sensation problem necessarily. It's kind of like a cognition problem. They might not necessarily acknowledge that side of their body ... Like they might draw half a clock, for example, and they would not draw the other half. Some things like that might cause problems, even if they can technically care for themselves"* (SLT-S-P21)

This condition of losing the ability to recognise parts of the body is a part of a larger syndrome known as hemispatial neglect, which is common among patients whose stroke affected the right parietal lobe of their brains (Parton *et al.*, 2004). Patients with this syndrome often experience a perceptual attention problem that prevents them from recognising and acknowledging stimuli from the contra side of the brain lesion (Parton *et al.*, 2004). These stimuli can include large objects, people and sounds, as well as the contralesional body parts (Parton *et al.*, 2004). Unlike other neurological conditions such as hemianopia, patients with hemispatial neglect are often unaware of being affected by this problem (Parton *et al.*, 2004). This syndrome has been shown to have a detrimental effect on patients' ability to undertake different basic daily life activities especially within the self-care domain (Nijboer *et al.*, 2013; Vanbellingen *et al.*, 2017). However, while this syndrome might have a significant impact on patients' oral care and oral health, there is a lack of evidence regarding the significance and the extent of this impact (Fujihara *et al.*, 2013).

While it is a normal practice in both NHS trusts to provide oral care assistance for dependent patients, it was reported by those interviewed that some patients appeared not to take an active approach to ask for help, even when they perceive the need for that, which may compromised the quality of oral care provided to them. Several explanations for this behaviour have been suggested. For example, participants have indicated that patients might assign a low priority to oral health as a result of the significant changes in their lives, which are perceived by them to be more worthy of focus. This explanation is supported by many studies that have explored stroke patients' priorities for scientific research and none of them reported that oral health or oral care is one of these priorities (Tan *et al.*, 2006; Sangvatanakul *et al.*, 2010; Pollock *et al.*, 2014). In addition, participants in this study have indicated that patients may not seek assistance to protect the medical team from the oral care burden.

> *"I don't necessarily think it [oral health] would be the first thing that they think about when they've had a stroke … [and] I think patients perceive staff as being too busy on the ward to ask, and they feel like they might be being a nuisance"* (Dental nurse-S-P24)

However, the passive approach was not always thought to be due to the low priority of oral health, as some of the participants' attributed the passive approach to the deterioration in patient's verbal communication that could make it difficult for them to ask for oral care.

> *"Often they can't verbalise … They're not always as likely to say what they don't want you to do, or what they would like you to do as far as tooth brushing goes"* (Dental therapist-N-P12)

The effect of the patients' passive approach (i.e. due to priority and communication ability) on oral care difficulties is consistent with several studies that explored the barriers and facilitators to providing oral care for dependent elders in care homes (Niesten *et al.*, 2013; Tham and Hardy, 2013). Nonetheless, in this study, nurses (i.e. the main providers of regular oral care) did not link this passive approach to oral care difficulties, even though they acknowledged the existence of this behaviour in some patients. This is possibly because nurses believe that an optimal oral care service should not require an active approach from dependent patients. Thus, they genuinely think that this passive approach does not have any impact on the quality of oral care. However, it is also possible that they were only concerned that by admitting this link, the reputation of their work quality could be threatened.

Even when oral care is offered to patients after stroke, those interviewed felt there was a subset of those patients who may refuse it. Several reasons were proposed by the participants to explain this refusal from the patients' side. For example, some patients might refuse the provided oral care to maintain their independence. Maintaining independence was perceived by the participants to be significant in relation to oral care because of its private nature.

> *"Regarding oral health, one, it depends, it's a very private part. So, they are aware of people intruding into their private area, they can't physically do. Over time they might be more receptive to others helping them because we all are proud people, generally we don't like people to help us and stuff like that"* (Dentist-S-P23)

This type of refusal could also be explained from the dependent adults' perspective who suggested in previous studies that they usually refuse the assistance in oral care to preserve a sense of dignity through maintaining a degree of autonomy and self-control after becoming dependent (Niesten *et al.*, 2012; Niesten *et al.*, 2013). These reports are also supported by findings from qualitative studies investigating the effect of dependency on adults, which have shown that receiving assistance can induce a sense of shame in individuals who are dependent on others due to the discrepancy between what dependent adults perceive they should be and what they actually are (Ågård *et al.*, 2012; Lykkegaard and Delmar, 2013).

There was a perception that other patients may refuse oral care if it induces and results in pain and discomfort. However, in some cases, a patient may not explicitly refuse the oral care, but it is withheld by the medical team when they notice the patient demonstrating signs of pain during the oral care process that are interpreted as a refusal from the patient.

> *"It's a vicious circle really if they're refusing mouth care because the mouth gets dryer, gets sorer and it's difficult to try and overcome that problem"* (Acute nurse-N-P10)

> *"You know, say you go to a patient and you go to brush their teeth, and they're "Ow, ow, ow", you're probably not going to brush it for as long as you would on someone who didn't have pain"* (Acute nurse-N-P13)

While withholding the oral care is not an effective approach to manage orofacial pain, it shows nurses' desire to elevate the pain experienced by their patients. The motive of this desire can be attributed to the fact that nurses usually demonstrate empathy towards patients experiencing pain (Watt-Watson *et al.*, 2000). However, this empathy does not necessarily translate into an effective pain management practice if nurses are not knowledgeable about the best approaches to manage the pain (van Dijk *et al.*, 2017; Germossa *et al.*, 2019). Thus, as some of participating nurses in this study may lack an adequate knowledge about oral care and orofacial pain management, this could explain why they have adopted this ineffective approach.

Patient refusal might be presented as an uncooperative and challenging behaviour by patients towards oral care, which can occur as a result of cognitive disturbances in patients after experiencing a stroke. Aggression is commonly observed among patients after stroke, which is known as post-stroke anger proneness (Stone *et al.*, 2004; Kim, 2016).

> *"Often whenever carers come in they'll [patients' caregivers] say, "We tried to brush their teeth," or perhaps that time they weren't amenable or they weren't cooperative … Bearing in mind after having a stroke, it might have implications on a patient's mental status or mood or behaviours, so again they might have episodes where they've got quite challenging behaviour or again they might be quite uncooperative. So, providing oral care in the home setting might be difficult"* (Dentist-N-P14)

However, uncooperative behaviours in post-stroke patients are not only demonstrated as aggressive, but also as manifestations of the patient's inability to cope with oral care procedures. Examples of these manifestations are patients who are unconscious or having difficulty in keeping their mouths open.

> *"I personally would say in general patients on the ward the most neglected part of the body is the mouth … Probably because of patient non-compliance or any muscular issues, like, they're not able to open their mouth properly"* (Dentist-S-P23)

Lastly, original attitudes toward oral care is another possible factor that was suggested by the interviewees to explain why some patients refuse the oral care provided to them.

> *"Maybe they didn't do it [oral care] before they came in … They might think, "Why am I doing this now?" If it's not normal for them, it's difficult"* (Rehabilitation nurse-N-P7)

> *"You know, I've had patients where I'll go and say, "Can I brush your teeth?" And they just refuse … I just think they've never brushed their teeth anyway"* (Acute nurse-N-P13)

In general, all the aforementioned reasons for oral care refusal in this study are consistent with many other studies that investigated dependent adult oral care in care homes (Niesten *et al.*, 2013; Tham and Hardy, 2013). In addition to the numerous aforementioned reasons for refusing oral care, other studies have suggested that dependent adults may refuse oral care if they do not appreciate the importance of oral care at this stage of their lives (De Visschere *et al.*, 2015).

The difficulties around undertaking oral care for post-stroke patients could result in a decline in their oral health status. These oral care difficulties are not only a result of patient-related factors but also as a consequence of service provider-related factors and environment-related factors, which are discussed in detail in the next two themes (Sections 6.5.2 and 6.5.3).

The difficulties in providing oral care were suggested to mainly result in poor oral hygiene, oral dryness and thrush build-up in patients' mouths. This was then suggested to lead to the potential for: higher incidences of pathological deterioration in patients' anatomical oral structures (e.g. dental decay and gingival inflammation); change in aesthetic appearance and or mouth odour.

> *"A big problem that we noticed … was that, people if they're not having their mouths cleaned frequently, they get quite dry secretions. So, a really dry, secretion filled mouth, cracks in their lips because their mouth is so dry"* (SLT-S-P20)

> *"Normally, if they've got bad breath, that's a sign of poor oral hygiene, so we try to get on top of the mouth care"* (Acute nurse-S-P17)

However, some participants, especially working within acute settings, did not recognise the impact of these difficulties on aesthetic appearance. This might be because patients usually do not spend a long enough time in the acute wards to experience a decline in their oral-related aesthetic appearance.

The findings regarding oral health status decline are in agreement with cross-sectional studies that have investigated the oral health status in patients after stroke, especially aspects such as dental plaque accumulation, oral thrush accumulation and gingival conditions (Dai *et al.*, 2015b; Kothari *et al.*, 2017).

The direct consequences of oral care difficulties (i.e. poor hygiene, dryness and thrush accumulation) alongside the pathological deterioration of anatomical oral structures are suggested as one of the main causes of pain and discomfort in the orofacial area in post-stroke patients.

> *"I think sometimes when we've had patients that have had oral thrush, sometimes they've complained of pain because it can obviously cause discomfort"* (SLT-N-P15)

> *"It's [the pain] normally a dental cause, dental or periodontal. Loose teeth, you know, pulp style pain, related to normally a prolonged period of dental neglect or dental disease which has been there for a long time, including before the stroke"* (Dentist-N-P2)

There is a shortage of published evidence about orofacial pain in patients after stroke, which limit the potential to contrast this finding with the wider literature. The lack of evidence about orofacial pain in patients after stroke may be attributed to the absence of a measurement instrument that can validly and reliably identify and assess pain in dependent post-stroke patients (especially those experiencing communication difficulties) (Delpont *et al.*, 2018).

Oral care difficulties can also negatively affect the patient's ability to perform oral functions such as eating and speaking. Eating ability was felt by interviewees to deteriorate as a result of the decline in the patient's oral hygiene and saliva quality.

> *"I mean if their oral health deteriorated if their dentures are unclean, or there's a build-up, and they have not a very nice taste in their mouth … If they've got thrush, for example, and their mouth is unclean, their tongue might be itchy, or the mouth feels and tastes horrible, so that might put them off eating and drinking because everything they eat just tastes horrible. If their oral health is poor, and it's all sticky, they might not be able to chew their food properly, because if their mouth's sticky and dry"* (SLT-S-P19)

In addition, patients' speaking ability has been suggested to decline as a result of the accumulation of saliva or thrush in their mouths. Mouth dryness was also reported to have a potentially detrimental effect on the patients' speaking ability.

> *"Although if they have got Candida or really thick secretions, I think then it can affect their intelligibility as well, and sometimes, patients who are thought to be dysarthric, it just turns out that their mouth isn't well-enough hydrated, or they have really thick secretions that are not being*

> *managed properly. So, yes, oral health does come into it sometimes, and then, once you actually give them some good mouth care, then their speech miraculously improves"* (SLT-N-P5)

The association between oral care difficulties and oral-related functional disturbances may be one of the novel findings in this study. This might be because previous studies have only investigated oral-related functional disturbances in relation to post-stroke neurological deficits (Dai *et al.*, 2015a; Schimmel *et al.*, 2017).

Lastly, losing dentures during hospitalisation was highlighted by the participants as one of the consequences of oral care difficulties. This finding is consistent with previous studies that have shown that hospitalisation is one of the main causes of losing dentures in the UK (Michaeli *et al.*, 2007; Mann and Doshi, 2017).

> *"They may have worn dentures previously. The dentures may have been lost during the time they've been in in-patients"* (Dentist-S-P22)

Impact of post-stroke neurological deficit and patients' general health on their oral health

Stroke can lead to a number of neurological deficits related to oral health that can subsequently result in oral-related functional disturbances. The motor weakness and consequential limited movement of the muscles in the orofacial area is the first type of neurological deficit suggested by the participants. The second suggested type was the deterioration in the sensory perception in the orofacial area. These two deficits usually occur if the stroke has affected certain parts of the brain, such as the precentral gyrus, Broca's area, Wernicke's area, motor and sensory cortex, striatum and internal capsule (Veis and Logemann, 1985; Martino *et al.*, 2005). Nonetheless, the participants also suggested that the decline in the patients' overall cognitive ability after a stroke can have a similar impact on oral-related functions. This subtheme discusses the oral-related functional disturbances that occur after stroke due to the neurological deficits, as well as their impact on the patients' oral health.

Disturbances in muscular function in the orofacial area was perceived by the participants to compromise patient's ability to eat and drink. Thus, the medical team may have to provide those patients with modified diets (e.g. pureed or fork-mashed food) and thickened fluid to facilitate eating and drinking.

> *"So, there will be some people, there will be quite a few people who, again, swallowing … chewing will be affected because of the neurological damage of the stroke"* (Physician-N-P4)

Problems with orofacial musculature control may also result in food pocketing and stasis, which subsequently can compromise patient's oral hygiene. This combined with the fact that those patients are usually offered an altered diet with high sugar content (i.e. to support their nutritional status), could contribute to higher prevalence of dental caries (decay).

> *"I think, obviously if they have got a facial weakness, potentially that might cause sort of more of a build-up in certain areas … obviously because the muscle tone inside the cheeks isn't necessarily pushing in towards the mouth, so even if they are eating and drinking, they might get a bit of a build-up or residue in one side, which potentially then could cause more of a problem"* (SLT-S-P21)

In addition, these muscular disturbances were reported to lead to the pooling of saliva in the patients' mouths. In contrast, other patients might experience hyposalivation when they are assigned to be nil by mouth as a result of their swallowing difficulty. Thus, they can experience dryness in their mouths because of restricted fluid intake.

> *"I suppose from my experience, I've seen patients although it might not necessarily be true hypersalivation or excess saliva produced, it might be that as a result of the stroke, they do get excess salivation. But it might also be sort of a pseudo-effect where again because of the stroke their swallowing is impaired, so they've got a normal amount of saliva. But again, those secretions are building up in the mouth, and then they suffer from drooling because they aren't able to swallow it"* (Dentist-N-P14)

> *"Because they can't swallow, the dry mouth. I can't think of anything else … Nil by mouth patients have more of the crusty mouth, dry mouth. They're not getting anything inside it, so that's when it becomes a problem"* (Acute nurse-S-P16)

Facial drooping is another manifestation of the muscular problems in the orofacial area that was reported to be not only aesthetically affects the patient's appearance but also may result in oral incompetence (i.e. food and drink dripping and saliva drooling) due to inadequate lip seal through lack of muscular control. The drooling of saliva may further cause mucosal irritation at the corner of patient's mouth.

> *"I think for some people they can have quite a pronounced facial droop, which can persist for some time after stroke. And obviously, I know for some patients that I've spoken to that that has impacted how they've seen themselves and obviously kind of not liking their appearance because they don't look like themselves. A facial droop can also lead to drooling, or having saliva escaping, which I think again people can sometimes be very self-conscious of and very embarrassed about"* (Rehabilitation nurse-N-P9)

Participants' reports of facial weakness and consequential impacts on eating ability are in line with other studies interviewed stroke survivors (Jacobsson *et al.*, 1996; Schimmel *et al.*, 2017). In addition, cross-sectional studies have demonstrated that approximately half of stroke survivors can experience some form of orofacial muscle impairment or weakness (Dai *et al.*, 2015a; Schimmel *et al.*, 2017). The deterioration in post-stroke patients' eating ability could be attributed to several factors, including a decline in chewing efficiency resulting from the need for increased chewing cycles and a longer oral phase than subjects in control groups (Kim and Han, 2005; Schimmel *et al.*, 2011b). In addition, data indicates that decreased sensation inside the oral cavity after stroke could contribute to food pocketing and a decline in eating ability (Leung *et al.*, 2002; Hirano *et al.*, 2004). Lastly, dysphagia (i.e. swallowing difficulty) following stroke is one major factor contributing to the eating difficulties with nearly half of post-stroke patients experiencing some form of dysphagia (Foley *et al.*, 2009; Konaka *et al.*, 2010).

Interviewees also described a decreased, or inability to speak as a result of muscular disturbance post stroke. This could range from a reduction in the voice quality to total speech absence. Losing the ability to speak is a common symptom in patients after a stroke, which, in many instances, occur as a direct consequence of the stroke incident itself (Pedersen *et al.*, 2004).

> *"Speech is massively affected with a patient that's had a stroke … Swallowing, yes. So, the part of the brain that affect your speech and your swallow can be affected, clearly, by a stroke"* (Acute nurse-S-P18)

In addition, participants felt that post-stroke patients with dentures might not have the muscular ability to retain the dentures in their mouths, which in turn could aesthetically affect their appearance and their ability to eat certain foods.

> *"Definitely their dentures. Because quite often if they've got a facial droop, you can't put their dentures back in … if a patient comes in and you can't put their dentures in, you know, you'd have to modify their diet"* (Acute nurse-N-P13)

> *"If they can't wear dentures, they could be left without having a good aesthetic appearance"* (Dentist-N-P3)

However, some of the participants with a medical background attributed the inability to wear dentures to weight loss experienced after a stroke. This may reflect some limitations in their knowledge about oral health and dentistry, which is discussed in more detail in the next theme (section 6.5.2).

> *"Will the dentures and stuff come in? Sometimes they don't have them or sometimes they don't fit them anymore because they've lost weight"* (Acute nurse-N-P11)

If the brain area controlling the sensory nerves in the orofacial area has been affected by the stroke, patients may feel discomfort in the orofacial area due to sensation alterations. These alterations can be manifest as a sensation of tingling or numbness. However, it has been suggested that patients with disturbances in their cognitive status might misinterpret these alterations as pain.

> *"A lot of people, they'll say … You've just touched them, and they'll say you've hit them because that's how they feel. That's how they feel it. If you touch their face, they'd say you've smacked them. You haven't; you've just literally touched. They think that you've really hit them hard because they're not fully aware of what … They just feel that somebody is there. So, they're thinking that you're actually hitting them, you're not, it's just that that's how they're sensing it"* (Rehabilitation nurse-N-P6)

This type of alteration in sensation is known as the central post-stroke pain syndrome, and reports about its prevalence among stroke patients ranged widely from 8% to 55%

(Singer *et al.*, 2017; Delpont *et al.*, 2018). The central post-stroke pain syndrome occurs in patients due to stroke-related injury to the pain-conducting pathways of the central nervous system including the brain, brain-stem and spinal cord (Harrison and Field, 2015; Singer *et al.*, 2017). While this syndrome can manifest as a tingling sensation, it can also cause genuine orofacial pain even in patients with no disturbances in their cognitive status, and can occur constantly, spontaneously or due to non-painful stimuli (Harrison and Field, 2015; Delpont *et al.*, 2018).

Deterioration in the cognitive status in patient after stroke could also result in oral functional disturbances similar to those resulting from the other types of neurological deficits.

> *"So, there will be some people, there will be quite a few people who, again, swallowing, speaking, chewing, will be affected because of the neurological damage of the stroke. Equally, that will be affected because of potential cognitive disturbance"* (Physician-N-P4)

The general health of post-stroke patients could play a role in their oral health status. For example, it has been suggested that the compromised immune system could lead to thrush accumulation. In addition, chest infections could compromise the oral hygiene of patients due to the accumulation of the mucosal secretions in their mouths.

> *"I think some of it is just the fact that their [post-stroke patients'] immune system is a bit compromised ... which obviously then can affect the balance of bacteria which can cause that [thrush] to grow"* (SLT-S-P21)

> *"A lot of them can get chest infections, coughing a lot. A lot of the time, if they can't clear their throats, you tend to find a lot of it can sort of pocket at the back of the throat. They need suctioning, extensive mouth care. We have suction toothbrushes to clean the teeth"* (Rehabilitation nurse-S-P30)

6.5.2 Service provider-related factors theme

There are several factors that can result in oral care difficulties for post-stroke patients related to the service providers. These factors include service providers' knowledge, attitude and priority, which are discussed in this theme.

Oral health and dental knowledge limitations among service providers with a medical background were suggested to potentially lead to oral care difficulties. However, this was mainly suggested by participants from a dental background, and thus may only represent their stereotypical views about the medical team members, which may not reflect the true reality.

> *"I don't want to criticise general nurse training, but by and large you don't know how much education the general nurses get in terms of oral care. Because I suppose doctors versus dentists, I know medics are not taught a great deal about mouths per se, so I am imagining the same thing applies for general nurses"* (Dentist-S-P22)

However, many participants from a medical background with different specialities and designations conveyed information during the interviews that reflected a less than optimal level of dental and oral health knowledge. For example, those participants indicated that oral care should be limited, reduced or implemented using ineffective methods (e.g. cotton wipe and sponge) for the patients after stroke who are nil by mouth to prevent aspiration pneumonia incidents. In addition, they suggested that dentures would not fit in patients' mouths in the acute phase due to weight loss (i.e. the acute phase usually does not last more than one week).

> *"That also can be compounded by the fact that even teeth cleaning can be so difficult after stroke because of risk of aspiration. So, whether we're using adequate alternative methods like cotton wipe or something to really regularly clean"* (Physician-N-P1)

> *"Will the dentures and stuff come in? Sometimes they don't have them or sometimes they don't fit them anymore because they've lost weight"* (Acute nurse-N-P11)

In fact, a cross-sectional study that investigated the level of dental and oral health knowledge among stroke ward nurses demonstrated deficiencies in their knowledge (Ab. Malik *et al.*, 2018). In general, limited knowledge about oral health and dentistry among medical service providers is one prominent cause of difficulty in providing oral care for dependent older adults (Göstemeyer *et al.*, 2019). Notably, this factor has been reported in a qualitative study conducted in care homes five years after implementing an intensive oral care programme (De Visschere *et al.*, 2015). In several previous studies, the lack of knowledge was usually attributed to inadequate oral care-related education and training during undergraduate education, as well as after graduation in the workplace (Yeung and Chui, 2010; De Visschere *et al.*, 2015; Hilton *et al.*, 2016).

Another suggested service provider-related factor that was reported is that some of the nurses may not recognise the significance and the importance of oral care for post-stroke patients, potentially limiting appropriate care.

> *"Another thing is ward staff they need to be trained about oral dental health and the importance of oral health and what are the associated complications because of lack of good oral health because not many people are aware that we are in risk of pneumonia and aspiration pneumonia and stuff like that which is one of the bigger medical issues in long term in patients"* (Dentist-S-P23)

However, the negative attitude of the nurses regarding oral care only represented the views of some dentists, physicians and speech and language therapists. Actually, none of the nurses in this study demonstrated a lack of appreciation of the importance of post-stroke oral care. Nonetheless, it must be noted that those nurses who might not appreciate the significance of oral care are also less likely to accept to take part in this study, and thus nurses' negative attitude may represent a true contributing factor in oral care difficulties. In fact, the limited knowledge of some nurses about oral health, which has been discussed in previous paragraphs, may contribute to establishing this negative attitude. This is consistent with qualitative studies conducted in care homes that reported adequate oral care may not be provided if the rationale behind it is not clear to the caregivers (De Visschere *et al.*, 2015; Hilton *et al.*, 2016).

It was suggested within the interview data collected that oral care might not be among the top priorities of medical team members when they are concerned with other medical issues perceived to be more important.

> *"Because I think sometimes, you know, because we don't provide care a lot, because if we're on an emergency, we're predominantly for the hyper-acute. But when we're not busy we will help out there. Sometimes you*

> *will go out and a patient's very dry, you know. And it is sort of like, how can we stop this happening?"* (Acute nurse-N-P13)

In line with this finding, it has been reported that even caregivers in care homes may view other personal care procedures to have a higher priority than regular oral care (Lindqvist *et al.*, 2013; Taverna *et al.*, 2014).

6.5.3 Environment-related factors theme

Factors related to the management and resources in the settings where healthcare is provided to post-stroke patients could play a role in oral care difficulties. In addition, medical treatments and interventions provided for patients after stroke could directly impact on their status of oral health.

Ambiguity over who is responsible for leading oral health and care management is another challenge in providing oral care for post-stroke patients.

> *"I think there's probably a bit of ambiguity about whose role it is in terms of looking after the patients. I think it's incredibly important ... I think it needs to be enforced a little bit more, and there probably needs to be more of a system for carrying it out and making sure that it's been completed"* (SLT-N-P5)

This was also supported by the inconsistent answers from the participants regarding who is responsible for the overall oral care and oral health management.

> *"Interviewer: Do you know what happened for the patients? Do you refer them for a dentist?*
> *Respondent: I think the doctor make the referral."* (Acute nurse-S-P16)

> *"Being a stroke physician, most of these complaint [about oral health] don't reach me, [and] are managed usually by ... nursing staff ... [I think] you might find more factual information about overall oral hygiene from nursing staff"* (Physician-N-P1)

This ambiguity usually occurs when there is no clear policy or legislation that explicitly states the roles of different service providers in providing oral care (Niesten *et al.*, 2013; Taverna *et al.*, 2014).

The limited number of staff and the unavailability of oral care tools have been suggested to result in providing less than optimal oral care for patients after stroke.

> *"Residential home on the whole tend to be poorer [in regard to oral health]. It could be staffing levels"* (Dental therapist-N-P12)

> *"Just in terms of equipment. I think … not so long ago, we didn't have equipment for patients. So, we struggled with having toothpaste, different types of toothpaste"* (Rehabilitation nurse-S-P30)

Studies conducted in hospitals and care homes have reported that one of the main barriers to providing oral care is limited time due to the heavy workload and the shortage in staff (Unfer *et al.*, 2012; De Visschere *et al.*, 2015; Horne *et al.*, 2015; Hilton *et al.*, 2016). However, within these studies, not all participants held this view as some of them suggested that the limited number of staff is only an excuse for poor time management skills and a negative attitude toward oral care (Taverna *et al.*, 2014; De Visschere *et al.*, 2015). The lack of availability of oral care tools as a cause of oral care difficulties was reported by a number of studies conducted in care homes and hospitals (Yeung and Chui, 2010; Taverna *et al.*, 2014).

Some medical treatments and interventions were reported as potentially causing a deterioration in the oral health of post-stroke patients. For example, intubation or placement of an orogastric tube could result in mucosal trauma that subsequently cause oral pain and hence, eating restrictions.

> *"It [orogastric tube] causes a scratch all the way down. Of course, they're frightened to eat and drink and swallow because it's sore. It sometimes takes time for that to heal"* (Rehabilitation nurse-N-P6)

In addition, using oxygen masks could increase the dryness of the patients' mouths.

> *"We've also got here patients that are on oxygen. They need more mouth care as well, because the mouth dries out, the tongue dries out. Because sometimes when a lot of ours have got chest infections, or they have come in with breathing problems and are on oxygen, their mouth becomes so dry"* (Acute nurse-S-P17)

Many medications prescribed for patients after stroke could have oral health-related side effects such as xerostomia. In fact, some patients are intentionally prescribed specific medications to reduce their saliva secretion, in order to reduce the risk of aspiration pneumonia. In addition, antibiotics that are prescribed to treat aspiration pneumonia and chest infections could contribute to the development of oral thrush in patients after stroke.

> *"Well, if they're at risk of aspiration, they can aspirate on their secretions, so they might potentially need hyoscine or something to manage their secretions, to stop them aspirating it, which can then cause dry mouth. So, it's trying to find the right balance of medication"* (SLT-N-P5)

> *"Maybe they have been on antibiotics, which obviously then can affect the balance of bacteria which can cause that [oral thrush] to grow"* (SLT-S-P21)

6.5.4 Oral health impact on patients' lives theme

This theme discusses the impact of oral health deterioration on different aspects of patients' lives, which include their general health, quality of life, behaviour and social interaction.

Poor oral hygiene has been suggested by the interviewees to impact patients' general health through increasing the bacterial load in the patients' mouths, and this has been linked to the increased risk of aspiration pneumonia, especially in patients with dysphagia.

> *"I think that there are a number of patients who have difficult dentition, and where that happens, we need to be careful with their oral hygiene after a stroke. And my understanding is that we're not providing good oral hygiene in patients, specifically where there's aspirational, aspiration that they will be more at risk of infection that may be more difficult to treat, and so it's important to provide oral hygiene as part of changing the biome that … potentially introduced into the lungs"* (Physician-S-P28)

This finding is supported by a growing body of evidence demonstrating the effectiveness of oral care interventions in reducing the risk of aspiration pneumonia in post-stroke patients (Seedat and Penn, 2016; Wagner *et al.*, 2016). However, there is still no consensus about the exact mechanism(s) of how the deterioration in oral hygiene causes aspiration pneumonia in patients after stroke (Van Der Maarel-Wierink *et al.*, 2013). Nonetheless, stroke-related neurological deficits, as well as mouths microbiome imbalance have been suggested to explain the growing risk of pneumonia due to poor oral hygiene in post-stroke patients (Lyons *et al.*, 2018; Mandell and Niederman, 2019).

In addition, as the deterioration in oral health can affect patients' eating and drinking ability, this has been perceived by the participants to impact patients' nutritional status, and thus their overall general health and recovery.

> *"And that in turn will affect overall improvement, because if they're not getting adequately hydrated and they're not eating well, that will affect rehabilitation in the long-term, yes I think it has a definite impact"* (Physician-S-P27)

Several studies have shown that patients can experience malnutrition problems after stroke (Lim and Choue, 2013; Sabbouh and Torbey, 2018). While the deterioration in oral health could be considered a major contributing factor in patient malnutrition, there are many other factors that might play a role (Sabbouh and Torbey, 2018). Examples include pre-existing malnutrition, presence of malignancy or comorbidity and reduced consciousness or mobility (Sabbouh and Torbey, 2018).

Furthermore, it has been suggested that patients with pain in the orofacial area would not want to perform physical exercises and the quality of their sleep might be disturbed. Thus, these consequences could negatively affect their overall physical recovery.

> *"Then it [orofacial pain] can really impact on mood and then that can impact on wanting to engage in rehab and get better from the stroke, so it can have really quite far reaching effects"* (SLT-N-P15)

> *"I think it'll affect their whole life. When you're in pain, it's not very pleasant; they might not be sleeping very well, they might not get their full rest ... I think their whole life will be affected by it"* (Hygienist -N-P8)

Lastly, the deterioration in oral health after stroke was linked by several participants to cardiac diseases.

> *"It can impact them from a cardiological point of view. I think there's evidence to suggest that, if patients have poor oral hygiene, it can actually have impact on their heart function"* (SLT-N-P5)

However, it must be noted that all the participants who have suggested this link were only reporting what they had read in the literature, not reflecting on real-life experiences. While there is evidence that link oral health deterioration to cardiac diseases, it has been criticised for potential residual confounding bias (Humagain *et al.*, 2006; Scannapieco and Cantos, 2016). In addition, none of these studies have specifically evaluated this link in patients after stroke (Humagain *et al.*, 2006; Scannapieco and Cantos, 2016).

Oral health deterioration and the lack of optimal oral care were reported to negatively affect patients' overall quality of life. However, the participants acknowledged that a decline in oral health status did not affect the quality of life for all patients equally. Factors such as the patient's original attitude toward oral health and oral care, as well as their medical status can impact how oral health problems affect the quality of life.

> *"It probably affects them a lot, I would've thought. Yes, I would think it would have quite a big, big thing on … It obviously depends on how much a person valued how they looked anyway. If it was somebody who always liked to look nice, and then they've had a stroke, and now they don't, I would think it would have quite a bad effect on them mentally. They might feel a little bit anxious and depressed, maybe. I would imagine that would be the case"* (Hygienist-N-P8)

While this finding was not reported by the patients themselves, it has substantial support in the literature (Schimmel *et al.*, 2011a; Dai *et al.*, 2017). The notion that oral health status would not affect the quality of life for all patients equally is supported by the qualitative evidence synthesis in Chapter 4, which indicates that variations in the impact of oral health on dependent adults can be attributed to the different values they place on that health.

Patients' behaviours were also felt by the participants to be negatively affected by their oral health status, especially when patients experience pain in the orofacial area, but cannot communicate it. Thus, post- stroke patients' ability to cooperate with their service providers might be compromised.

> *"Often the change in the behaviour with the patient, they may just stop cooperating with other stuff like general care, they may start to hit themselves because they can't vocalise, and also they may stop eating or drinking or refuse food"* (Dental therapist-N-P12)

There is evidence supporting the notion that pain could contribute to aggression and behavioural problems (Fernandez, 2005; Niel *et al.*, 2007). The disruptive behaviours may represent the way patients after stroke with communication difficulties to communicate their pain (Ahn and Horgas, 2013). In addition, neuropathological changes in patients' brains after a stroke could contribute to initiating this type of behaviour (Carota *et al.*, 2002).

Oral health deterioration was also reported by the interviewees to negatively affect patients' social interactions with others.

> *"Obviously, if they've had a stroke and they've got a weakness, the food falls out of their mouth one side. In speaking, if they know there's a problem, they might not want to speak as much. They might just sit and only speak when necessary"* (Rehabilitation nurse-N-P9)

> *"I know we've had patient reports to say when their mouth doesn't feel clean, they don't want to talk to people. They don't want to eat and drink. They just don't feel nice; they don't feel socially like they want to interact with people"* (SLT-S-P20)

According to the oral health conceptual model that was established based on dependent adults' input in Chapter 4, oral health does not directly impact patients' social interactions, but patients with a deterioration in their oral health status would limit their social interaction to preserve and maintain their social worth and hence their overall quality of life.

6.5.5 Summary of the main findings

This part of the qualitative study has shown that service providers perceived a decline in oral health status of many dependent patients after stroke. While there are many factors causing this decline, those related to dependency seem to be among the most significant ones, leading to difficulties in undertaking adequate oral care for post-stroke patients. The decline in oral health has been shown to be manifested in different oral health-related problems, which can be easily mapped to the four oral health domains in the conceptual model established in Chapter 4. This is because oral health problems reported in these patients (such as poor oral hygiene, orofacial pain and thrush build-up) are relevant to one of the four oral health status domains (i.e. structures, pain, functions, and noticeable aspects). Contrasting these findings with the scientific literature has shown significant similarities between the causes and manifestations of oral health decline between the dependent post-stroke patients and the wider dependent adult population.

Nonetheless, other causes for oral health decline in post-stroke patients have been suggested in this study. For example, neurological deficits after stroke can impact on patients' abilities to perform different oral-related functions. While these neurological deficits may not be relevant to all dependent adults, it can affect a substantial group of them who suffer neurological diseases such as multiple sclerosis or Parkinson's disease. In addition, patient's general health and medical treatment provided could negatively affect the post-stroke patient's oral health, and this is possibly applicable to the other medically compromised dependent adults.

Lastly, the decline in oral health can affect different aspects of post-stroke patient's life. This includes general health, quality of life, behaviour and social interaction. Even though this study lacked patient inputs, there is a huge similarity between the suggested impact in this study and in the qualitative evidence synthesis study (Chapter 4).

The triangulation of evidence from this study, the qualitative evidence synthesis study (Chapter 4) and other studies about oral health in dependent adults has demonstrated substantial parallel views. This would support the trustworthiness of the finding in this study. In addition, this can support the possibility to transfer the findings of this study to the wider population of dependent adults.

6.6 Data and Discussion Part 2: Service Providers' Perceptions about Oral Health Assessment in Patients after Stroke

This section explores the participants' views and perspectives about oral health assessment in post-stroke patients. It presents and discusses the current oral health assessment practice of service providers. In addition, it reveals and explores the factors that have been perceived to affect the implementation and application of oral health assessment for post-stroke patients.

6.6.1 Current practice theme

While neither of the two trusts have officially implemented an oral health measurement instrument, participants from both trusts spoke about their initiatives to assess their patients' oral health. However, the Salford Royal NHS Foundation Trust was in the early stage of implementing the Mouth Care Matters programme, which involves assessing the patients' oral health using a unique measurement instrument. This theme presents and discusses the current practice of assessing oral health for patients after stroke in both trusts.

Individual initiatives

Nurses and speech and language therapists spoke about their individual initiatives to perform oral health assessment for patients after stroke. Nurses tend to perform the assessment while performing oral care, in order to guide their oral care practice. Nurses reported that they usually assessed the patients' saliva quality and quantity, oral hygiene and presence of oral thrush.

> *"So just, there's no guidelines on it [oral health assessment], but I'm, you know, when, so basically when we wash patients and things like that, you know, that's what we do. We're looking in their mouth. Because I will give, brush their teeth, give them some suction if needed, moisten their tongue, get them some oral gel if they need it. If they look like they've got thrush, do they need some nystatin? So, it's a sort of ongoing daily thing that you do within your, you know, your patient assessment that you do with them every time you see them, basically"* (Acute nurse-N-P13)

Speech and language therapists, however, often undertook the oral health assessment while performing the swallowing and speech assessment, in order to guide the eating regime of those patients. Thus, besides assessing the oral hygiene of the patient, they also assess the patients' ability to perform different oral functions.

> *"With swallowing assessments, we are looking at conducting an oral motor assessment to see how people's anatomy and physiology in their*

> *mouth is working, which also informs us a little bit about how things might be working in the pharyngeal area as well, so we have to kind of conduct those kinds of assessments. And also looking at that point at oral hygiene and whether that's good or fair, or poor because that's going to impact on the decisions, I make about whether the person can safely eat or drink, or not"* (SLT-N-P15)

However, participants (i.e. both nurses and speech and language therapists) who have demonstrated a particular interest in oral health have also reported assessing other aspects of oral health such as patients' dental status and gingival and mucosal conditions.

> *"What I normally tend to do, I try and get the patient to open their mouth if they can, use a pen torch, have a look inside, ask them to put their tongues out if they can, check their tongues for thrush. Have a look to see if there is any red and dead, any infection, and especially if they have got bad breath. Sometimes that's a sign of a problem as well, without them expressing any pain. It could be a sign of gum disease that we haven't picked up on, or they've not been able to tell us that they've got it prior to coming into hospital"* (Acute nurse-S-P17)

None of the participants reported that they would intentionally assess pain in the orofacial area as part of their individual initiatives. However, some of the participants suggested that they would undertake actions if they suspect that a patient is experiencing pain.

> *"Sometimes, if the patient can't open their mouth, we need to be checking the patients' mouths, especially if they appear to be in pain. A lot of our patients have to express pain, because a lot of them lose their speech when they have had a stroke, so it's vital that we check the patient's mouth for pain, abscesses, gum disease, thrush, sore tongues, because it's not just about dental pain. Obviously, it's about mouth care as well, and mouth pain"* (Acute nurse-S-P17)

Other participants considered the pain in the orofacial area is already assessed as part of the general pain assessment, which is routinely undertaken for each patient. Though, some were sceptical about the efficiency of this general pain assessment.

> *"Respondent: We ask patients, on every observation round, if they've got pain. Every observation round, it's actually part of the plan on the observation round, we ask them if they've got pain. Then we have to ask them out of 10, 1 is not too bad, 10 is the worst pain you've ever had. You'll ask them 1 to 10, and it's always a 10.*
> *Interviewer: Do you think all patients have this severe pain?*
> *Respondent: No … You can tell by their grimace and their faces and how they are. You get to know your patients very quickly, and you know which ones are in pain and which ones aren't"* (Rehabilitation nurse-N-P6)

These reports about the service providers' individual initiatives may indicate that the participants appreciate to a certain degree the significance of oral health assessment for post-stroke patients. However, as these individual initiatives were only reported by nurses and speech and language therapists, this may suggest that there is an implied agreement between the medical team members that the tasks related to oral care and oral health are the responsibility of these two professions. This was particularly highlighted by a consultant physician's reply when asked about his role regarding oral health assessment.

> *"Being a stroke physician, most of these complaint [about oral health] don't reach me, [and] are managed usually by junior doctors and nursing staff … [I think] you might find more factual information about overall oral hygiene from nursing staff, speech and language therapists and junior doctors. Consultants should be aware of it, so if the questions come to them, they should be able to address and also raise awareness that it is important. Whether they directly look for the problems, I don't think, because of the prioritisation of work at a consultant level"* (Physician-N-P1)

It must be noted that these reports about the individual initiatives might not represent service providers who do not have the same level of interest regarding oral health and who are also less likely to agree to participate in this study. In addition, these reports do not necessarily reflect the quality or consistency of the assessments being done. For example, many studies have shown the accuracy of nurses' oral health assessments tend to be less than optimal if they did not receive adequate dental training and education (Munoz *et al.*, 2009; Gerritsen *et al.*, 2014), which is the case for the most nurses and speech and language therapists participating in this study.

The Mouth Care Matters programme in Salford

The Mouth Care Matters programme is a national initiative that aims to improve oral health in dependent patients both in hospital and community care settings (Quinlan, 2017). This programme was in its early stage of implementation in the Salford Royal NHS Foundation Trust. The main motive to adopt this programme by the trust was to reduce the incidence of aspiration pneumonia among hospitalised patients. In general, this programme has been perceived positively by the participants from this trust.

> *"We've collected the hospital-acquired pneumonia data for the last five years, and we are going to compare it monthly from now on, with the implementation of Mouth Care Matters"* (Dental nurse-S-P24)

> *"It's [the Mouth Care Matters programme] very good. Because actually, most patients who, whether they are a stroke patient or a dementia patient, previously they've probably had very little input into their oral health"* (Dentist-S-P22)

Part of this programme is a measurement instrument that is used to evaluate the oral health of hospitalised patients to guide the establishment of their oral care plan. This instrument was initially developed by Health Education England (Quinlan, 2017). However, even though neither the measurement properties nor the interpretability of this instrument was evaluated, it has been adopted by the Salford Trust. The trust has adapted and modified the instrument to fit its working environment. For example, the scoring system was changed to a numerical one. In addition, the instrument has been adapted into an electronic format.

> *"We met as a steering group and we included some extra, because we know that nurses apparently like things to be numbered, whereas this tool was like a low, medium and high, a L, M and H. But nurses prefer … well at Salford Royal, I presume it's everywhere but I don't know … they*

> *like things to be numbered … [Also] the problem we've found here is Salford is very much a digital trust and we don't have much paper. The nurses on the ward have been a bit reluctant because going back to using paper again and everything else is on the computer … [the leading team] have done a lot of work making the assessment tool electronic"* (Dental nurse-S-P24)

In general, this instrument assesses different aspects of oral health weekly, and based on the obtained score, a specific oral care protocol is followed.

> *"What had happened, so anything that was kind of like low risk, or say you are looking at the lips, they are pink and moist, you would score that as a one, whereas if they were ulcerated you'd maybe score them as a three or a four. You'd have the different subheadings, and we'd have to decide on scores. Then depending on what you've clicked in the boxes, it will calculate the score, and it will come up with a care plan. We have got a low-risk care plan, a medium, a high risk and palliative care. It will come up with that care plan and pop it into the patient's notes"* (Dental nurse-S-P24)

However, it was not possible during this study to investigate in depth the participants' perceptions about the instrument and the overall programme because they were still in the early stage of implementation. In fact, many participants at the time of their interviews were not aware of the existence of the programme and the instrument. In addition, exploring the implementation and usefulness of the programme and its measurement instrument was beyond the scope of this study.

6.6.2 Importance of oral health assessment theme

Participants appreciated the importance of adopting an oral health measurement instrument to guide oral care planning for post-stroke patients, and they have identified many advantages of adopting such an instrument. First, assessing oral health was perceived to change the medical service providers' attitude regarding the importance of oral care and oral health, especially if they notice the oral health problems experienced by post-stroke patients.

> *"It [oral health assessment] will be huge because at the minute I don't think the wards see oral care as part of the personal care. They give somebody a wash and they brush their hair, but they don't seem to think the mouth needs cleaning as well, particularly stroke patients"* (Dental nurse-S-P25)

Oral health assessment was also suggested to prompt the medical service providers to undertake regular oral care, which can improve the oral health status and prevent the negative impacts of oral health deterioration.

> *"I think it makes people look and see what needs doing. Then if they are taking the time to check oral hygiene, then they are more obliged to carry out sort of routine care"* (Rehabilitation nurse-S-P26)

Appreciating the role of using an oral health measurement instrument in enhancing the quality of oral care provided for dependent patients is consistent with several studies that interviewed service providers and caregivers from different settings (Reis *et al.*, 2011; Horne *et al.*, 2015). It can be argued that the impact of using an oral health measurement instrument on the service providers' attitudes and actions is a result of improvement in their knowledge about the significance of oral health and the way of undertaking a better and more effective oral care practice. In fact, the significance of improving knowledge for clinical intervention success can be manifested by the existence of education as an essential domain in most implementation models and behavioural change theories in the healthcare field (Michie *et al.*, 2011; Flottorp *et al.*, 2013).

It was noteworthy how the speciality and designation of the participants associated with unique justifications about the importance of using the oral health measurement instrument in relation to oral care. For example, participants with administrative roles and those responsible for providing regular oral care attributed the importance of the oral health assessment to its ability to improve the quality of oral care provided.

> *"I think it's really important because I think, at the moment, the nursing staff are doing basic oral care, but if they had an assessment tool that said, "What do the lips look like? What does the inside of the mouth look like? The tongue, the palate? What's the dentition like? Have they got*

> *any lesions? Is it dry? Is it moist? What is their eating and drinking status like? Are they 'nil by mouth'? Are they high risk or deteriorating?" … So, I think an assessment tool's really, really important, because it makes the nursing staff and the patients look at key factors relating to the mouth care"* (SLT-S-P19)

On the other hand, other medical service providers attributed the importance of the oral health assessment to its potential role in improving the general health and overall quality of life in patients after stroke.

> *"If we were going to look more at stroke-associated pneumonia and how that's defined, then looking at oral health and assessing that more formally, and perhaps with a particular instrument would be helpful in understanding an instance of pneumonia"* (Physician-S-P28)

Lastly, participants from the dental field recognised the significance of oral health assessment in relation to its impact on the patients' oral health status.

> *"I suppose it's [oral health assessment] really important in this group that there are appropriate things put in place at an earlier stage so that those at risk are picked up and highlighted. Then we can provide the patient and any support, family or care staff with the relevant information and trying to maintain oral health in a way as best we can"* (Dentist-N-P14)

An oral health assessment was also suggested to help in enhancing the quality of care by allowing the medical team to assess the oral health of independent patients without concern about violation their autonomy and independence.

> *"If someone's self-caring, they can independently clean their teeth, and you have a quick look in their mouth, and everything's fine, then they're quite low risk"* (SLT-S-P19)

This suggestion was based mainly on the notion that not all patients after stroke are dependent upon others, and thus providing oral care assistance for all patients can result in impinging on the quality of life of some partially independent patients who would like to maintain their autonomy and independence by undertaking oral care themself (Section 6.5.1). This can be particularly true in the healthcare systems that follow a paternalistic approach when providing care (Entwistle *et al.*, 2010; Murgic *et al.*, 2015).

Another potential advantage for the oral health assessment is that it can help in documenting the oral care provided for patients after stroke in a systematic way. Improving the quality of documentation was considered by the participants to be important from the legal and auditing perspectives. In addition, it was suggested that documenting oral care may help in improving the quality of care by ensuring that each patient is receiving oral care.

> *"I think so we know what's been carried out, so then when patients, you know, if we get complaints and things, we can look back to see what cares have been carried out. We also want to encourage people to document if care has been refused as well because it can be refused"* (Dental nurse-S-P24)

Documentation is an essential component in modern healthcare practice (Cheevakasemsook *et al.*, 2006). Besides the aforementioned advantages proposed by the participants, there are other potential advantages from enhancing the quality of documentation such as establishing a database that can be utilised to support the development of nursing knowledge, planning future healthcare and risk management (Cheevakasemsook *et al.*, 2006; Jefferies *et al.*, 2010).

Only one nurse from the Newcastle Trust did not recognise any importance of a standardised oral health measurement instrument. Even though this nurse acknowledged that many post-stroke patients experience a decline in their oral health, she believed that the current oral care practice is adequate to maintain the patients' oral health, and thus introducing any measurement instrument would be extra work with no potential benefit.

> *"Interviewer: What do you think about using an instrument or screening tool to guide the oral care planning for patients after stroke?*
> *Respondent: We do automatically ... It comes, all, with the same care plan. Personal care, it's like a personal care plan. They have speech and language, they have showers, baths, and things, and oral care all comes together"* (Rehabilitation nurse-N-P6)

6.6.3 Oral health assessment barriers theme

The participants in this study reported many barriers that can hinder the assessment of oral health for patients after stroke. These barriers mirror those discussed in Section 6.5 in relation to providing oral care. The similarity between the barriers can be attributed to the fact that oral health assessment is just a task within the overall oral care. Therefore, barriers to the oral health assessment have been arranged and briefly presented in this theme similar to those in Section 6.5.

Communication problems in post-stroke patients due to neurological or cognitive deficits was one of the barriers suggested to hinder the implementation and use of an oral health assessment. This was considered especially true in the assessment of orofacial pain due to the subjective nature of pain. It was mentioned that it could be difficult to know if patients with communication difficulties are experiencing pain in the orofacial area, as well as to locating and identifying the exact source or cause of that pain in those patients.

> *"It's hard to assess pain objectively because it's a very subjective thing about how someone feels about their mouth, so it can be hard to assess pain if someone's having difficulty communicating that after a stroke"* (SLT-S-P19)

Participants have also suggested that some post-stroke patients might refuse or be unable to cope with the oral health assessment for several reasons. These reasons are similar to those discussed in section 6.5.1 regarding difficulties around undertaking oral care.

> *"It's not always easy to assess a patient's mouth because they don't always let you in it ... Some patients just don't like anything in their mouth, especially when someone else is doing it for them. Some patients actually refuse"* (Acute nurse-N-P11)

> *"There are some people who have got quite marked oral sensitisation and won't let you look in their mouth. So, I'm guessing that, from the point of view of an elderly population, with potential for TMJ dysfunction there may be difficulties physically opening their mouth"* (Physician-S-P28)

To overcome these patient-related barriers, participants have proposed many suggestions about how the measurement instrument should look like and who should perform oral health assessments. These suggestions are presented and discussed in the next themes (Sections 6.6.4 and 6.6.5).

It was suggested that the medical service providers might not feel confident about their skills and knowledge to perform oral health assessments, which may prevent them from undertaking those assessments. This suggestion was mainly reported by participants with a dental background, and thus the implications of these reports are similar to what has been discussed in section 6.5.2 about medical service providers' knowledge and oral care difficulties.

> *"One, it's [oral health] an area that they're not familiar with. As part of their general nurse training, I don't know how much input they get about mouths, oral pathology, dental care"* (Dentist-S-P22)

> *"But then I would say that being just a general ward doctor, I don't think I'd be very good at doing a proper dental assessment because I wouldn't know all the stuff that needs to be looked at"* (Physician-S-P27)

Offering oral health-related education and training for the medical service providers were perceived to be important for the success of the implementation of the oral health measurement instrument as the service providers might not have the adequate knowledge and skills to undertake these assessments. Generally, participants thought that the initial training and education should focus on selected members of the medical team who can be then responsible for educating and training other medical service providers. This was suggested due to the perceived difficulties in providing the training for the whole medical team at once. The participants valued the theoretical and practical aspects of training and education by indicating the need for lectures and hands-on sessions for medical service providers.

> *"I think the difficulty that I have, especially in the nursing ways of working, is having the whole team available to be part of training. The way I always see training is that you would identify champions or people who are able and willing to take on an element of care and champion it so other people can ask of them. So, they would gain training and they*

> *would become trained trainers, if you will, so they're able to lead on education and support of the staff ... I think that you could provide specific sessions, you could provide PowerPoint sessions, practical sessions"* (Rehabilitation nurse-S-P29)

The perceived unfavourable attitude and low priority of medical service providers toward oral health and care is another factor that was thought to reduce their willingness to perform oral health assessments.

> *"I would like that to change. I would like patients, as well as all the healthcare teams, to view mouth care and mouth health as very important. If everybody thinks it's more important, then it might become more normal for people to ask about it, to expect to be asked, and people might be more happy answering the questions. I think most patients would be so used to having so many various medical teams and colleagues asking them questions and doing various assessments"* (Dentist-N-P2)

Thus, to have a successful implementation, participants believed that there is a need to raise awareness among the medical team about the importance of oral health and its assessment for patients after stroke. This could be done by explaining the potential impact of the oral health assessment on the quality of oral care provided, as well as its positive impact on patients' oral health status, overall general health and quality of life. Raising awareness can also be supported by telling real patients' stories that demonstrate the significance of oral health and oral care for them after stroke.

> *"It's another form, "Why am I doing this?" But actually, with a good education system and a good training system, good patient stories of horrific mouths or somebody saying how much pain they were in, you know, whatever the experience is, then it relates that assessment to real life, and I think that would really support it being carried out"* (SLT-S-P20)

The significance of education and training for the success of implementation is well recognised in scientific literature and they represent essential domains within most implementation and behaviour change theories (Flottorp *et al.*, 2013; Atkins *et al.*, 2017). In fact, in a study exploring facilitators and barriers for implementing screening tool among emergency nurses, knowledge was among the most important factors (Kirk *et al.*, 2016). In addition, several studies have shown that education improves service providers confidence and competence as well as the quality of care provided (Griscti and Jacono, 2006; Fletcher, 2007).

Because stroke wards have limited staff, the interviewees thought that the medical team may not have the time to incorporate an oral health measurement instrument into their practice. In addition, if the use of the measurement instrument requires specialised tools such as dental mirrors, this could be another potential barrier for the assessment because these tools are not usually available outside dental settings. To overcome these barriers, participants provided many suggestions regarding simplification of the measurement instrument, and hence improve its feasibility and usability in the stroke wards (Section 6.6.4).

> *"Time. I think time would be a massive barrier, because I think they already do so many assessments. I think there are more and more things put on the nursing role"* (SLT-S-P20)

> *"We don't have mouth mirrors, so we wouldn't be able to use that [oral health measurement instrument]"* (Acute nurse-N-P11)

In addition, if the implemented oral health assessment is not part of the trust's policies and standard operating procedures or is not compatible with the working environment, this could be another potential barrier for successful implementation.

> *"It should be part… so, most assessments in care are now provided within, in protocols and standard approaches. So, it would be to ensure that it is part of a stroke unit's normal practice. Where possible, with standardised documentation"* (Physician-N-P4)

Participants have acknowledged that there are other possible barriers they had not considered. Thus, they suggested that before the implementation stage, it would be beneficial to run a pilot test of the oral health measurement instrument to reveal potential problems that could be sorted out before the official implementation.

> *"Maybe trial it on wards and see how they get on wards and see how they get on with it. We do a lot of that here if there's something new. Certain wards will trial it, and if it's a good outcome, then they'll roll it out to the whole Trust. Yes, put it together and just see how it goes, yes"* (Acute nurse-S-P18)

The importance of pilot testing of new medical interventions through undertaking exploratory studies is well recognised (Sanson-Fisher *et al.*, 2007; Kessler and Glasgow, 2011). However, a recent systematic review of existing recommendations and guidelines about exploratory studies has shown that these recommendations and guidelines are not always comprehensive or consistent (Hallingberg *et al.*, 2018). Thus, undertaking a robust exploratory study to evaluate the feasibility of using the new measurement instrument may not be an easy task.

Then, once the instrument is implemented, continuous auditing is needed during and after implementation to determine if assessments are performed correctly, and no new problems have arisen.

> *"I think that if you were then planning weekly visits to see how things were going that you might just check up on technique … So, you'd want to be tending to that, perhaps as part of a weekly visit to see how people are getting on with this. To actually have a look at the tool and the documentation, to have a look at how it was being administered and how well the oral health prescriptions"* (Physician-S-P28)

While clinical audit has been widely advocated to improve the quality of medical care, current evidence does not clearly support the proposed effectiveness of clinical audit (Esposito and Dal Canton, 2014; Paton *et al.*, 2015). In fact, a Cochrane systematic review consisting of 140 studies that test the effectiveness of clinical audit found widely variable outcomes ranging from a negative to very positive effects (Ivers *et al.*, 2012).

6.6.4 Measurement instrument's features theme

This theme presents and discusses the features of oral health measurement instrument reported to be important for successful implementation and application. These features include suggestions regarding specific aspects the instrument should assess. In addition, they include descriptions of the instrument's characteristics and input methods.

Aspects to be assessed by the measurement instrument

Participants recommended that the oral health problems occurring in post-stroke patients (detailed in section 6.5) need to be assessed by the oral health measurement instrument.

> *"Yes, so it's important to do a general assessment of the dentition to see any existing restorations or any new holes or new decay lesions. It's important to assess the oral soft tissues for any sores, spots, patches, ulcers, anything that might present as potentially sinister that that's appropriately reviewed or, if necessary, it's referred for further investigation … Are the gums bleeding or is there a lot of plaque or do they notice a lot of accumulation around the teeth? I think that's a general thing to look out for"* (Dentist-N-P14)

However, not all participants agreed that all oral health problems need to be assessed as part of the measurement instrument. For example, it was suggested that it might not be beneficial to assess oral health problems such as simple dental caries, that cannot be treated or rectified within the hospital setting.

> *"What would be very difficult for a patient is if somebody says, "Oh, I want to talk to you about your mouth. Have you got these problems?" and they say, "Yes," and then we say, "Okay, fine. Well, we know you've got a broken tooth, but we can't do anything about it." That's when it's difficult. I think patients would find it very frustrating if we had a detailed list of what problems they've got and then weren't able to do anything about it"* (Dentist-N-P2)

In addition, participants reported that it is not necessary to assess the aspects of oral health already assessed by other instruments (e.g. the ability to swallow and speak).

> *"So, I think swallow I wouldn't be happy with adding for a stroke patient, because swallow is being assessed in quite a lot of depth … all of our patients have a swallow assessment as part of their admission. And so, I would see this would be something that is already being looked at on a separate issue … I would feel that that would probably be duplicating something that is already being done. Voice, again, I think that's quite*

> *subjective, so a deep or rasping voice, or difficulty talking or painful, then, again, voice we look at in articulation, so look for dysarthria. And again, that's something that speech and language therapists would look at further if there was an issue with voice production"* (Physician-S-P28)

Furthermore, oral health problems perceived as not prevalent among post-stroke patients were not viewed as sufficiently necessary to be included in the oral health measurement instrument (e.g. orofacial pain).

> *"Interviewer: What do you think about assessing and measuring orofacial pain for dependent patients after stroke?*
> *Respondent: Right. I don't think it's a major clinical problem … In my clinical experience, it is not something that has been a problem. It is not pain; it is poor hygiene that's the problem"* (Physician-N-P4)

Besides oral health problems, the participants also suggested to measure and record the risk factors that can cause oral health deterioration in post-stroke patients as part of the oral health measurement instrument. For example, they thought it necessary to record if a patient is experiencing neurological deficits that could lead to oral functional disturbances.

> *"So, the only other thing would be maybe to highlight if they are nil by mouth or not, maybe, because obviously many of us, if their swallowing is affected, do end up being nil by mouth. I don't know whether you could add it as a category or whether you can just add it maybe as, is the patient eating and drinking, or are they nil by mouth? Just at the top"* (Physician-S-P27)

In addition, they suggested that the new measurement instrument needs to record if the patient is experiencing any general health condition or receiving any medical treatment or intervention that can impact their oral health status.

> *"[The assessment should include] any oral health conditions, any medication that they're on that might lead to worsening dry mouth conditions that we need to be aware of, because some medications cause more dry mouth"* (SLT-S-P19)

Another risk factor proposed for assessment by the instrument is the patients' ability to perform oral care independently. Lastly, recording via the measurement instrument if a patient has and wears dentures was viewed to be necessary. The recording of these risk factors was considered to be crucial because they can significantly affect the nature of oral care provided to the patients after stroke.

> *"[The assessment should include] how much assistance they need, so whether they are fully independent, whether they need some assistance, like either bringing the mouth care products to them in bed, or if the patient can get up, they are fully independent, they can go to the bathroom"* (Dental nurse-S-P24)

> *"Sometimes patients have dentures in and they haven't known that there are dentures in their mouth, so obviously to make sure that is recorded whether they have dentures or not"* (SLT-S-P21)

Many participants believed that the oral health measurement instrument needed to document the oral care provided for dependent patients after stroke. This was perceived to be important because it would allow for improvement in the overall quality of care.

> *"I would probably have a tick box type thing, things that you do twice a day. Some patients might have dentures, so you would need to go over denture care and show them how they've got to be kept clean. So, you tick the box every night, that the dentures have been taken out, they've been cleaned thoroughly and they've been sterilised. Then, hopefully, the next morning the patient will have their teeth cleaned, and tick the box"* (Hygienist-N-P8)

The suggested aspects to be measured in this study is considerably different from the previously developed oral health measurement instruments for dependent adults (see Table 5.6 in Chapter 5). For example, participants in this study have pragmatically limited the number of oral health problems to be measured as part of the measurement instrument. This limitation was mainly undertaken in order to utilise the NHS trust resources in the most effective way. In addition, they have suggested to assess other aspects that are not part of the oral health construct, but were viewed to be significantly relevant to oral care planning such as assessing risk factors for oral health. These differences between the findings in this study and previously developed measurement instrument might be attributed to consideration of medical service providers' inputs in this study; who have not been consulted during the development of many of those previous instruments (Kayser-Jones *et al.*, 1995; Tsukada *et al.*, 2017).

Characteristics of the measurement instrument

Even though some participants in this study acknowledged that developing an oral health measurement instrument that is simple and comprehensive at the same time is not an easy task, there was an overwhelming agreement between the participants that the oral health measurement instrument needed to be as simple as possible because this could play a significant role in overcoming several barriers when assessing oral health in patients after stroke. The simplicity of the oral health measurement instrument was suggested to be achieved by designing it to be easily used and understood.

> *"I think prior to this you need a shorter screening, something simpler, maybe just a few questions … Which I know is difficult to do because there are a lot of things that need to be covered, but maybe something very simple, a few questions to use a screening tool"* (Physician-S-P27)

> *"I think it does need to be simple and clear for non-dental professionals. I think we need to mindful that"* (Dentist-N-P2)

Participants suggested the usability of the measurement instrument could be optimised by being as brief as possible. Thus, particular attention should be paid to the number of questions or items in the instrument, as well as the overall word count. In fact, some participants suggested that the entire instrument should be presented on a single sheet of paper.

> *"There's a lot to read through. When you work on a very busy ward like this, I think it could do with being simplified a bit"* (Acute nurse-N-P10)

> *"Then we streamlined it into two pages. There was a separate box for recording palliative care things, so we took that out just to streamline it. It was easier for them just one sheet of paper on the front and the back"* (Dental nurse-S-P25)

Some participants believed that developing a measurement instrument with standardised approach by providing a specific item for each aspect of patients' mouth that needs to be assessed would enhance the usability because this can highlight the important aspects of oral health that may not be recognised by service providers from a medical background.

> *"Because actually, if you are not a dentist, then you may not think it's important to check all of these things. Whereas, we know if we're looking at oral pathology, you would go around the mouth in a- Everybody has their own way of doing it so that you cover all the structures in the mouth. So, if you're not a dental professional, you may not understand the reasons for doing that. Whereas, if you set them out, look at the patient's lips, then you look at the tongue- So, that means that you pick it up, you turn it from side to side, and you look underneath it"* (Dentist-S-P22)

However, other participants believed that by including too many items in the instrument, this might increase the time required to complete it, and thus compromising its feasibility and usability.

> *"It would be the oral tissues we would combine into one group. Lips, tongue, gums and tissues. Sort of bringing all those together and simplify, because I think that's quite detailed, which is good, but for somebody with a lot of residents or a busy session, that's quite a lot to do. Yes, it's very detailed"* (Hygienist-N-P8)

Another suggestion to improve the usability of the instrument was to simplify the method of recording instrument scores. For example, some participants suggested using a tick-box format. Others recommended using pictures of the mouth to mark the problematic area of oral health.

> *"I would probably have a tick box type thing, things that you do twice a day"* (Hygienist-N-P8)

> *"We have a computerised electronic patient record at Salford, and we've got lots of printed maps of mouths. The easiest thing is to have a map of a mouth and then you mark on the map so that if you see something that*

> *you think is abnormal, you just mark it across on the picture. So, it means that somebody else coming along can look at the same place and know that there isn't any abnormality. So, I think the simpler you make it, it makes it easier for people to use the tool"* (Dentist-S-P22)

In addition, participants valued the clarity of the instrument's layout because this could have a significant impact on the instrument's usability. This was reflected by the participants' comments regarding the layout of The Holistic and Reliable Oral Assessment Tool (THROAT) (Appendix M: Measurement instrument 3).

> *"I don't like that one. That's [font size] too small, I don't like that. I don't even think I need to read it; I don't like it"* (Acute nurse-N-P11)

> *"Well, it's harder to read, for one, just because it's badly laid out, I think"* (SLT-N-P5)

Improving the comprehensibility of the oral health measurement instrument was the other aspect considered to be necessary regarding the instrument's simplicity. Many participants believed that the new instrument should match the knowledge level of the service providers who would undertake this type of assessment.

> *"In the past, when I've worked in another trust, we had oral hygiene in the care plan for admission when you're filling in the admission book. I've got to admit, I was newly qualified and I didn't understand any of the words that they used, the terminology. I think sometimes you just need to simplify it for people to understand, especially when they don't specialise in that area. If it's healthcare, if they notice it, to be able to act on that and report to us. I think some things just need to be simplified"* (Acute nurse-N-P11)

In addition, it was thought that providing instructions on how to undertake the assessment (i.e. this could be in a written format or photographic images of the oral health conditions) would help in improving the comprehensibility of the instrument.

> *"Even if there were some images on the screen of the things you might be looking out for, to help nursing staff identify whether their patient's tongue or their mucosa is abnormal in any way"* (SLT-N-P5)

The measurement instrument input method

It has been suggested that it could be easier to directly ask post-stroke patients about their oral health status especially if they do not experience any problem with their communication.

> *"Asking patients, so if the patient is in a position to talk again, that makes the job a lot easier … If the patient is in a position to understand what's happening or in a position to communicate, then they would tell us exactly."* (Dentist-S-P23)

For patients who experience difficulties verbally communicating their responses, participants suggested visual aids be used that can enhance communication with those patients. However, these communication aids have been criticised by some participants who thought that they are not always a valid communication mean to use with patients after stroke.

> *"I think we'd need to use all possible ways to get that information. You'd have to have questions that were very simple, whether they could write things down or you could use picture boards as well. We often use picture boards with patients where you can put up pictures, your smiley faces where they're happy with the appearance, and then they can elaborate on that. Oral function thumbs up or thumbs down. It's using different communication aids. Maybe more pictures. Some patients communicate fine with a stroke. The other extreme, people may just want to write things down, or I would use pictures"* (Dentist-N-P3)

> *"I think it's not an ideal measure [visual pain scale]. It's also, I think sometimes with patients that can't communicate, sometimes it's not necessarily reliable anyway because you're now always sure if they've understood what you're asking of them"* (SLT-N-P15)

On the other hand, for patients who cannot communicate due to cognitive reasons, it was suggested that it would be necessary to adopt a more clinician-reported approach. However, this could be particularly problematic when assessing the orofacial pain in those patients due to the subjective nature of pain. Thus, the participants have suggested several techniques to assess the pain in the orofacial area. One of the suggested techniques was to observe patients' behaviours during eating, drinking or the oral care process.

> *"I know it sounds really bad, but sometimes if a patients has got a stroke and cannot communicate, it's hard to know exactly where the pain is, and obviously you can brush someone's teeth, and if they're wincing or anything, you can obviously put that down to them having pain ... but, yes. Yes, it's quite difficult to identify where, yes, specifically, especially if they can't communicate, it's just, yes"* (Rehabilitation nurse-S-P30)

> *"It could be behavioural issues, changes in behaviour or touch, things like that. They may refuse eating. They may refuse toothbrushing, so they flinch on toothbrushing. Constantly pointing or tapping. You see a swelling, certain obvious"* (Dentist-N-P3)

Other suggested looking for signs of pain after intentionally initiate it through palpating areas that are suspected to be the potential sources of the orofacial pain.

> *"I would look in, and I'd be looking for teeth that, if I push on, they've got an obvious pain response or any sharp or broken teeth which are causing traumas or mucosa. Those are my main concerns. I think for somebody that can't tell you whether or not they've got pain, we need to look at their behaviour, and if their behaviour could potentially be affected. If they're holding their face, if they're visibly distressed, then we'd need to be a bit more proactive"* (Dentist-N-P2)

There are several advantages of adopting a patient-reported approach when measuring health to guide patient's care plan (Deshpande *et al.*, 2011; Ní Ríordáin and Wiriyakijja, 2017), which may explain why some participants have advocated using this approach. First, this approach can help in empowering patients and facilitating provision of a more patient-centred care (Deshpande *et al.*, 2011; Kingsley and Patel, 2017). In addition, it can be more useful than the clinician-reported approach when evaluating a medical intervention mainly aiming to enhance the patient's quality of life such as treatments provided for end of life patients. Furthermore, it has been suggested that patient-reported approach is more accurate than other approaches when assessing symptoms that cannot be directly observed such as pain (Deshpande *et al.*, 2011; Kingsley and

Patel, 2017). In fact, several studies have shown that this approach is the most sensitive one when measuring cancer-related symptoms (Flores *et al.*, 2012; Bhattacharya *et al.*, 2019).

However, as this approach is highly dependent on patient's physical and psychological states, any deterioration in those may adversely affect the measurement accuracy of this approach (Kingsley and Patel, 2017). This can explain why many participants in this study have advocated using the clinician-reported approach to overcome the communication difficulties experienced by many post-stroke patients. The decline in measurements accuracy when utilising the patient-reported approach could also be a consequence of patients worry about the impact of their responses on the care provided (Kingsley and Patel, 2017). These concerns about the accuracy of patient's responses might be applicable to all dependent adults, which may explain why all the oral health and orofacial pain measurement instruments identified in Chapter 5 have adopted the clinician-reported approach.

6.6.5 Characteristics of assessor theme

The participants felt that completing the oral health assessment needed to be assigned to specific members from the medical team to ensure that it is done consistently. However, they also agreed that all the medical team members should be able to perform the assessment.

> *"Having said that, it is everyone's task, but you have to put the name against the task so that it's consistently done"* (Physician-N-P1)

Participants considered a number of factors when choosing the preferred speciality of the service providers who should perform the assessment. One suggestion was that the assessment should be performed by providers with the minimum skills and knowledge necessary to successfully administer it.

> *"I think that would be probably maybe more easy for a medic that is more trained or is maybe orally aware … how they would assess that"* (SLT-S-P21)

The participants also proposed that the assessment should be performed by service providers whose roles and duties are congruous with this type of assessment.

> *"I think the nursing staff are in a really good position ... But anyone who has a clinical responsibility for documenting the health of the patient, or whoever is admitting that patient, whether it be a doctor, an advanced nurse, an advanced practitioner"* (SLT-S-P19)

Lastly, other participants believed that service providers who spent the most time and had the most frequent contact with the post-stroke patients were the best candidates to perform the oral health assessment. This is because patients are familiar with those service providers and thus patients are more likely to accept being assessed by them. In addition, this could help in preserving the NHS resources.

> *"No, I think nurses should just be doing that, because physios go to the patients maybe for 10, 15 minutes in a day, doctors go to them probably around the same. It's the nursing team that see the patients more, have more dealings with the patients, probably know the patients better. So, for me, it should just be the nursing side of it"* (Acute nurse-S-P18)

6.6.6 Frequency of oral health assessment theme

Participants in this study expressed two distinct views regarding the optimal frequency for performing the oral health assessment in patients after stroke. While some participants preferred the assessment occurred at the same frequency for all patients, others believed that customising the frequency for each patient would be more beneficial.

The rationale given by participants supporting a fixed assessment frequency for all patients was mainly to ensure consistent assessment, as a more flexible approach may result in patients being overlooked.

> *"People might think, "Oh it [oral health assessment] was done yesterday. And because you can't guarantee where people are admitted and discharged, you couldn't say ... Because they might not be there on time"* (SLT-S-P20)

The participants advocating the fixed approach suggested varying frequencies, from twice per day to once per week. The variation in suggested frequencies could be attributed to the differences in participant reasoning. For example, some participants suggested that the frequency of the oral health assessment should be similar to that of other assessments of post-stroke patients.

> *"Well, at the moment, we have quite a comprehensive stroke pathway where certain assessments are carried out routinely when patients are admitted under stroke. And I think oral hygiene and oral care should be part of that initial assessment"* (SLT-N-P15)

In contrast, other participants suggested that the frequency of the assessment should represent the minimum period required for a change in oral health status.

> *"I'm going to suggest you need to do it at least every other day. It's a long time a week, isn't it? Anything could change; the patients could get an ulcer. If they're stroke patients if they can't tell you, you might see an ulcer or something is not right"* (Dental nurse-S-P25)

While other participants adopted a more pragmatic approach by suggesting that the frequency of the oral health assessment should follow that of the daily oral care. This is because the oral care can provide regular opportunities to look at the patients' mouths, and thus the care and assessment can be performed simultaneously.

> *"I think it's done twice a day … I think the general rule is that you brush your teeth twice a day. You brush your teeth twice a day, because that is recommended by dentists, isn't it? While you are brushing that patient's teeth you are having a look in their mouth, aren't you, so it just follows that you'd do it twice a day"* (Rehabilitation nurse-S-P26)

On the other hand, the other participants suggested that the frequency of oral health assessment should be tailored for each patient. This dynamic approach was suggested to improve the efficiency and effectiveness of the service provided to the patients.

> *"I think having a standard routine volume of interventions as a necessity it would be useful. I think that the problem that we have there is that by blanket, sort of, covering every patient, we're going to miss those ones that need a little bit more intervention or could be promoted to do things more themselves. So, there's two; there's vice versa, it could either be detrimental to the patient's rehab, or it could be that having a standard*

> *timeframe, you're not actually going to do the interventions required to prevent damage or areas of concern"* (Rehabilitation nurse-S-P29)

> *"I think you probably could divine*[2] *a flowchart of what to do, and who to do, and repeat. I'm not a fan of, do something every week or do everything every month, to everybody, because that's a waste of resource"* (Physician-N-P4)

In general, there were two lines of thought regarding which criterion to be used to determine the assessment frequency for each patient. Some participants suggested that the frequency should be based on the scores of the oral health assessment performed at the time of admission.

> *"I think definitely on admission we should be looking at mouth and I think that it would be safe to say that we should be commenting on that within each nursing evaluation would be my thought, it's a basic standard of nursing care. Obviously, we use a RAG-rating system, red, amber, green, so patients who are lower risk … would be lead to them increase or decrease the amount of assessments you do per day. I think for someone who is a very high risk or due to poor dentition, poor oral hygiene, I think that a minimum of at least a physical assessment that's commented on should be done at least three to four hourly"* (Rehabilitation nurse-S-P29)

Others believed that the frequency should be based on any change in the patient's general condition that could create a risk to oral health.

> *"You'd get the mouth care ready, and you would still do it, but then you would have to look at the next patient and just say, "They've been on antibiotics. Keep an eye on their tongue. Have they got a chest infection?" You would look at each one individually, and just adjust their care plan appropriately"* (Acute nurse-S-P17)

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[2] Perhaps the participant meant to say design.

6.6.7 Oral care planning theme

The ability to produce a feasible oral care plan based on the assessment outcomes was considered to be crucial to successfully implement the oral health measurement instrument.

> *"I think we just need to be mindful that, if we pick up on all of the problems and we find out a patient has a condition, we do have a duty to try and help manage that. Otherwise, a screening tool is pointless if we can't do anything about the outcome. So that needs to be very seriously considered to figure out how we help people and what we can do to benefit this group of patients"* (Dentist-N-P2)

Some participants believe that there is a need for rigid guidelines to help establish the appropriate care plan based on oral health assessment outcomes. This was suggested by the participants from the medical field to overcome the limitations in their dental knowledge as some had raised concerns about their inability to correctly interpret assessment scores.

> *"If it wasn't then, obviously, we would know how to follow that path, but having a specific plan to say ... I don't know. I think a lot of people like having specific care plans with algorithms with what to do next"* (Rehabilitation nurse-S-P30)

> *"Yes, it's good. I like it. It's good just to get the scores and then generates ... But then what do you do with it? You know, that's the problem"* (Acute nurse-N-P13)

This view from participants may indicate that they prefer to adopt the prescriptive decision-making approach, the most common approach for decision-making in the nursing field (Luker *et al.*, 1998). This approach usually utilises decision trees or algorithms that produce clinical decisions based on probability calculations of every decision outcome (Müller *et al.*, 2003; van der Sanden *et al.*, 2004). However, utilisation of this approach might be limited when it is not possible to establish a clinical guideline due to the lack of conclusive scientific evidence. In addition, this approach does not consider social and environmental factors, or any other beyond the biomedical algorithms (McKinlay *et al.*, 1996).

However, other participants believed in a more flexible approach when establishing the oral care plan by discussing the outcome of oral health assessment among a multi-disciplinary team, which can also involve patients and dental services providers to make decisions about the required actions. The rationale for this suggestion was to attempt to establish oral care plans that better suit each patient's needs.

> *"Or what we do is we design a care plan to fit round the patient's routine, so go in whichever time of day is best for the patient, and we go in, and then we go and check in maybe about a month's time to see how they are getting on. We can maybe jiggle that care plan again to suit the patient"* (Dental therapist-N-P12)

> *"Care plans that aren't individualised and are based upon standard documentation don't allow for those normal variants that you see in nearly every patient"* (Rehabilitation nurse-S-P29)

This flexible approach is more subjective, and it is consistent with the descriptive decision-making approach. This approach depends on the clinician's knowledge, experience and intuition (Easen and Wilcockson, 1996). While this approach can potentially maintain a more holistic view during the decision-making process, it can present a higher risk of different types of biases due to its subjective nature (McKinlay *et al.*, 1996).

Several oral care plan actions were suggested by the participants to be undertaking based on the outcomes of the oral health assessment. One of these actions was to adjust the frequency of subsequent oral health assessments. This was mainly proposed by participants who have advocated for the dynamic approach for determining the frequency of the oral health assessment.

> *"I think if it's a nurse doing it, and then they're acting on it, then it will get, they'll incorporate it into their daily care plan. So, they'll say, this patient's scored high on their overall assessment, so I need to be conscious of checking their mouth every, more frequently than someone who hasn't"* (Acute nurse-N-P13)

The actions in the oral care plan can also include undertaking or adjusting oral care interventions that are performed either by the nurses or the multidisciplinary team based on the complexity of the oral health conditions.

> *"It [oral care plan] depends what the problem is really, doesn't it? If their mouth is sore, what you'd do to overcome that problem. Sometimes we have mouthwash that we use. Obviously, we'd have to get it all prescribed by the doctor. If it's just dryness, increase the amount of mouth care that you'd give to a patient"* (Acute nurse-N-P10)

Oral health problems that cannot be managed by the multidisciplinary team because they are beyond the team's roles, skills or knowledge were suggested to be referred to dental professionals.

> *"So, there's a chain again. If somebody is brushing their teeth on a daily basis it's seen as a daily assessment and they can always flag it up. Anything that's out of the normal they can always flag it up to the ward nurses who kind of escalate it to the doctor in charge and they can access dental services"* (Dentist-S-P23)

Nonetheless, the lack of collaboration between the medical and dental team is a barrier to involving dental professionals in establishing the care plan and referring patients to them. While there was a clear desire from both medical and dental personnel to establish this collaboration, none of the participants were aware of any existing pathway for referring patients between the medical and dental teams.

> *"We do find this quite challenging because obviously we don't have always – not all hospitals have dentists there … unfortunately many a time if it is something that can be left, we tend not to then do it and then we signpost them and say that once they're discharged we will liaise and get checked with the dentist"* (Physician-S-P27)

There are other barriers that may also prevent the dental team from providing their services to patients after stroke. For example, accessing dental settings may not be possible for immobile patients.

> *"Then you've got the issues of a dental hospital, such as here, doesn't have chairs really with hoists, and wheelchair transfer is more complicated in this building. We're the building into the hospital, so if everyone was assessed, there wouldn't necessarily be a route by which everything could be managed"* (Dentist-N-P2)

In addition, general dental practitioners may not have adequate knowledge and skills to treat and care for patients after stroke.

> *"You could get someone from the emergency department at the dental hospital could go along and see patients. It depends on their skill and their ability to treat patients like that; often, they can be complex because they may be on blood thinners and things like that. If you can get a specialist dentist, that would be the most appropriate, I personally feel. There's no reason why someone else couldn't go; it just depends if they'd feel comfortable treating or assessing a patient."* (Dentist-N-P3*)*

Investigating the details of barriers to providing dental treatment for post-stroke patients was beyond the scope of this study. There are many other barriers to providing dental treatment for dependent individuals that have been discussed in previous qualitative studies and were not identified during this study. For example, it has been suggested that dependent elders' lack of motivation and belief in the result of dental treatment may reduce their willingness to seek it (Niesten *et al.*, 2013; Tham and Hardy, 2013). In addition, the limited dental treatment provided to dependent adults may also result from financial barriers (Paley *et al.*, 2009; Tham and Hardy, 2013).

6.6.8 Summary of the main findings

In this part of the qualitative study, the importance of oral health assessment for post-stroke patients was emphasised. This importance was attributed the assessment's positive impact on the service providers' understanding and attitude toward oral health and the quality of undertaking and documenting oral care provided. In fact, the participants' appreciation of the importance of oral health assessment can be manifested by their initiatives to assess their patients' oral health. However, implementing and using an oral health measurement instrument for post-stroke patients has been viewed as a complex task because of several barriers. These barriers can be related to patients, service providers or the environment in which care is being delivered. Participants considered the unique features of the measurement instrument, characteristics of assessors and frequency of assessment to be the most important factors for overcoming these barriers and for achieving successful implementation and application. In addition, they appreciated the importance of the ability to establish feasible oral care plans based on the measurement instrument's outcomes for the instrument's implementation success.

6.7 Study Limitations

There were a number of limitations in this study that may weaken its applicability and transferability (Hammarberg *et al.*, 2016). For example, as the findings of this study were based on the views of service providers who work within the NHS, the ability to transfer the findings to settings with different healthcare models is likely to be limited. In addition, professional caregivers in care homes and family caregivers in the community were not represented in this study, which may also limit the transferability of the findings into these particular settings.

Another limitation of this study is that it did not recruit post-stroke patients, and thus information about them was based only on service provider perceptions, which may not exactly triangulate to those of the patients who were being cared for.

Lastly, even though a purposive sampling technique was utilised in this study, it is not possible from an ethical perspective to adopt a “true” purposive approach. This is because it was the participant’s decision to take part in the study, and thus it is possible that service providers with a greater interest in oral health were more inclined to participate in the study.

6.8 Conclusion

This qualitative study revealed that dependent post-stroke patients from the perspective of service providers usually experience a decline in their oral health status, potentially attributable to the difficulties in performing and receiving appropriate oral care. In addition, the general health condition of the patients, and the medical treatment they receive was thought to play roles in compromising patients’ oral health. This decline in patients’ oral health can affect multiple aspects of their lives significantly. Thus, the participants in this study clearly described the importance and significance of an oral health assessment for dependent post-stroke patients to guide their oral care planning. This can also be demonstrated by their individual initiatives to assess their patients' oral health. However, the participants anticipated that the implementation of an oral health measurement instrument is not easily produced because of many potential barriers. Therefore, to successfully implement and apply an oral health measurement instrument for dependent post-stroke patients, different factors need early consideration, including those beyond the measurement instrument itself. These factors concern the users themselves, the receivers of the instrument, the environment where the instrument will be implemented and applied, and the establishment of deliverable oral care plan.

Chapter 7. General Discussion

7.1 Key Findings of the Research and Their Implications

Dependent adults who are reliant on others for self-care due to a reduction in their mental capacity or physical capability can experience many oral health problems, which could impinge on their general health and quality of life. This is supported by numerous epidemiological and qualitative studies (Chapter 2, Section 2.3.1), as well as reports from the qualitative evidence synthesis (Chapter 4, Sections 4.4.4 and 4.4.5) and the qualitative interview study (Chapter 6, Section 6.5). The plethora of oral health problems experienced by dependent adults can be partially attributed to the challenging nature of providing them with regular oral care (Chapter 2, Section 2.3.2). While there are many barriers that could explain why there is a difficulty with providing them with oral care, one of the most prominent barriers is caregivers' lack of knowledge about oral health and oral care (Yeung and Chui, 2010; Horne *et al.*, 2015; Göstemeyer *et al.*, 2019). Thus, caregivers from previous studies suggested that to overcome this barrier, there is a need to develop an oral health measurement instrument that can help in establishing oral care planning for dependent adults (Hijii, 2003; Horne *et al.*, 2015; Smith and Thomson, 2017; Andersson *et al.*, 2019). This suggestion was also proposed by the participants in the qualitative interview study (Chapter 6, Section 6.6.2). In fact, these participants believed that utilising such an instrument could offer many other advantages in regard to patients' health and wellbeing, as well as the quality of care provided to them (Chapter 6, Section 6.6.2).

To address the need for an oral health measurement instrument that is capable of guiding oral care planning for dependent adults, eight different instruments have been previously developed (Chapter 5, Table 5.4). These instruments were developed to be used by non-dental caregivers and, for most of them, their main purpose was to guide oral care planning for dependent adults. It was not clear, however, if they were developed to overcome caregivers' limited dental knowledge or only to highlight the need for dental referral (Chapter 5, Table 5.4). Although the first instrument was published in 1995 (Chapter 5, Table 5.2), none of these instruments has been widely used in daily clinical practice. This might be attributed to flaws in their development procedures (Chapter 5, Section 5.5.1). In addition, the lack of strong evidence supporting their measurement properties, interpretability and feasibility might be another barrier preventing them from being successfully implemented (Chapter 5, Sections 5.4.6 and 5.4.7).

From the work in this thesis it could be argued that the most important barrier, preventing these instruments from being successfully implemented, is that they have been developed and used without in-depth consideration of how they would fit within the existing models of care. This might be because the developing teams were primarily focused on establishing an instrument that could ideally measure oral health and, thus, could perfectly fulfil the dependent adults' needs. Interestingly, in the qualitative interview study (Chapter 6, Section 6.6), the issue regarding how to fit a new instrument into an existing model of care was the main concern that shaped most of the participants' answers regarding how the oral health measurement instrument should be designed and used. Comparing and contrasting evidence from the three studies in this PhD thesis is a step toward comprehending aspects such as the measurement instrument's content, format, frequency of use and users in relation to the possible tension between the desire to perfectly fulfil the dependent adults' needs and the inevitable limitations in care with which they could be provided. Thus, the emerging evidence from this thesis can contribute to developing a new oral health measurement instrument that achieves the right balance in relation to this tension.

According to the oral health conceptual model established in Chapter 4, oral health from the dependent adults' perspective is a multidimensional construct that the data within this thesis suggesting it consists of four domains: the intactness and cleanliness of oral structures, oral pain and discomfort, oral functions and noticeable oral health aspects. Theoretically, to develop an oral health measurement instrument for dependent adults with ideal content validity, all oral health problems relevant to any of these domains that could be experienced by dependent adults should be measured and evaluated. This is supported by De Vet *et al.* (2011, p. 42) who stated that to support the content validity of any measurement instrument, there is a need to include as many relevant items as possible. The weights of these different domains in the oral health measurement instrument may not necessarily be equal because dependent adults are likely not to assign equal value to all of these domains (Chapter 4, Section 4.4.7). Even though participants in the qualitative interview study appreciated the advantage of comprehensively measuring all aspects of dependent patients' oral health, they highlighted the importance of utilising the NHS trust recourses in the most effective way to fulfil the dependent patients' needs and provide them with the best care they can (Chapter 6, Section 6.6.4). Therefore, they adopted more pragmatic views by suggesting that the oral health measurement instrument should only assess the aspects of oral health that could be incorporated into their oral care planning (Chapter 6, Section 6.6.4). In addition, they believed that the oral health measurement instrument should not assess aspects that are not prevalent among dependent patients or are already assessed by other instruments (Chapter 6, Section 6.6.4).

The developing teams of the previously published oral health measurement instruments were possibly erring on the idealistic side when establishing the content of their instruments. This can be manifested by the relatively large number of items included in these instruments (Chapter 5, Table 5.4). In fact, during the qualitative interview study, several participants thought that some of these instruments were too lengthy to be practically used in their clinical settings (Chapter 6, Section 6.6.4, first and third quotes in page 208). However, even with these instruments being relatively lengthy, they might not comprehensively measure the dependent adult's oral health. This is because most of these instruments' items focus on only measuring aspects related to the domain of oral structure intactness and cleanliness (Chapter 5, Table 5.6). In addition, although oral pain and discomfort is thought to be the most important domain from a dependent adult's perspective (Chapter 4, Section 4.4.7), it was evaluated by only one instrument (Chapter 5, Table 5.6). Thus, the assessments obtained using these instruments may not truly reflect the oral health status and needs of dependent adults. Furthermore, even though participants in the qualitative interview study advocated for evaluating several risk factors that could lead to oral health deterioration in dependent patients (Chapter 6, Section 6.6.4), none of these factors formed part of the previously published oral health measurement instruments (Chapter 5, Table 5.6). Examples of these risk factors include experiencing neurological deficits, general health deterioration, receiving certain medical interventions, and a decline in the patient's ability to perform independent oral care (Chapter 6, Section 6.6.4). The participants in the qualitative interview study advocated evaluation of these risk factors because this could help in establishing effective oral care plans that could prevent oral health deterioration (Chapter 6, Section 6.6.4). Thus, to develop a successful oral health measurement instrument for dependent adults, the oral health risk factor, as well as the oral health problems (especially those most important for dependent adults) need to be considered. In addition, the development procedure should take into account the tension between the idealistic and pragmatic views.

The brevity of the oral health measurement instrument (through limiting the aspects measured by the instrument, which could reduce the instrument's number of items) was not the only suggestion that the participants made in the qualitative interview study to improve the instrument's simplicity and, subsequently, feasibility. Participants also suggested eliminating the need for specialised tools (e.g. dental mirrors) when using such an instrument (Chapter 6, Section 6.6.4). However, as several of the identified instruments in Chapter 5 require such tools, this may play a role in limiting their potential to be successfully implemented. Moreover, another suggestion to improve the instrument's simplicity was to improve the clarity of the layout, as well as to use a recording method that is easy to complete (e.g. tick-box format) (Chapter 6, Section 6.6.4). Even though all of the published oral health measurement instruments utilised a tick-box recording method, participants in the qualitative interview study were not always satisfied with other aspects regarding these instruments' layouts (Chapter 6, Section 6.6.4). Thus, the simplicity and clarity of the instrument are important characteristics that need to be considered when developing an oral health measurement instrument for dependent adults.

The ability of an assessor to comprehend the content of a measurement instrument is another important aspect to ensure its implementation success (Flottorp *et al.*, 2013). However, when exploring who the most appropriate professionals are to complete the oral health measurement instruments for dependent patients, having excellent knowledge about oral health and care was not widely considered to be among the most important criteria (Chapter 6, Section 6.6.5). The criteria perceived to ensure high assessment consistency were the coincidence between the assessor's duties and roles and the nature of the assessment task, as well as the ability to have frequent contact with the dependent patient (Chapter 6, Section 6.6.5). Medical nurses and support workers are most likely to be the professionals who can meet these criteria to the highest degree. This may explain the presence of their independent and individual initiatives to assess oral health for dependent patients in the qualitative interview study (Chapter 6, Section 6.6.1). In addition, it may explain why most of the developing teams (of the published oral health measurement instruments) developed their instruments to be used by these professionals (Chapter 5, Table 5.4). However, because nurses and support workers may not have extensive knowledge of oral health and care, this may adversely affect their ability to comprehend oral health measurement instruments and their ability to complete them accurately and utilise them effectively (Chapter 6, Section 6.6.3).

Therefore, efforts need to be made to bridge any gap between the assessor's knowledge about oral health and the instrument's comprehensibility. This can be delivered by providing dental training and education for assessors to enhance their knowledge (Chapter 6, Section 6.6.3). However, because there are potential limitations in providing such training and education (Ward and Wood, 2000; Sarre *et al.*, 2018), efforts should also focus on improving the general comprehensibility of the instrument itself (Chapter 6, Section 6.6.4). The inability of the assessors to understand the measurement instrument's content may explain the inadequate reliability of some oral health measurement instruments identified in the quantitative systematic review (Chapter 5, Section 5.5.2). Thus, for any new oral health measurement instrument, three relevant factors (i.e. instrument comprehensibility, the assessor's knowledge about oral health and care, and dental education and training provided) should be considered in relation to each other to bridge any potential gap and improve the instrument's overall comprehensibility.

Selecting the appropriate input method for any measurement instrument (i.e. patient-reported or clinician-reported) has the potential to contribute to its implementation success (De Vet *et al.*, 2011, p. 11). While the patient-reported approach has the advantage of capturing how individuals perceive their conditions easily and accurately (Deshpande *et al.*, 2011; Ní Ríordáin and Wiriyakijja, 2017), it has not been used in any of the identified oral health measurement instruments included in the quantitative systematic review (Chapter 5, Table 5.4). All of these oral health measurement instruments have adopted the clinician-reported approach (Chapter 5, Table 5.4). This might be because many dependent adults experience communication difficulties that could compromise the accuracy of the measurements obtained using the patient-reported approach (Chapter 6, Section 6.6.3).

Nonetheless, the clinician-reported approach may have a limited application if used to assess the orofacial pain domain of oral health due to the subjective nature of pain (Chapter 6, Section 6.6.4). To overcome this limitation, many of the participants advocated for using visual aids to improve communication. However, other participants questioned the validity of these aids (Chapter 6, Section 6.6.4). Others advocated for monitoring dependent patients' behaviour during different situations to assess their orofacial pain (Chapter 6, Section 6.6.4). This approach has been utilised in all of the orofacial pain measurement instruments identified in Chapter 5 (Table 5.7). Among these instruments, the Orofacial Pain Scale for Non-Verbal Individuals (OPS-NVI) has the strongest evidence to support its measurement properties (Chapter 5, Table 5.18). However, because this instrument is relatively lengthy (64 items) and requires 12 minutes on average to be completed (Chapter 5, Table 5.5 and Table 5.22), it may need further simplification before being widely and easily used to guide oral care planning for dependent adults. In summary, because most dependent adult populations could experience communication problems, adopting the clinician-reported approach might be advisable. However, for certain populations who do not experience such problems, the patient-reported approach may be more beneficial.

While the frequency of completing an oral health measurement instrument was not specifically discussed in the studies included in the quantitative systematic review (Chapter 5), this issue was explored extensively in the qualitative interview study (Chapter 6, Section 6.6.6). In this study, there were two distinctive views regarding optimal frequency. The first view was adopted by participants who advocated for having a fixed frequency for all dependent patients to ensure consistency. Others suggested customising the frequency for each dependent patient to improve efficiency (Chapter 6, Section 6.6.6). Integrating these two views on frequency may help in establishing a frequency system that is simultaneously efficient and effective. This can be done if the oral health measurement instrument is divided into two parts: one that evaluates the risk factors for oral health deterioration, and another that evaluates different oral health conditions. Completing the first part might only be necessary when a dependent adult is admitted to a new setting or when there is a change in his/her general condition. This approach of assessment frequency is similar to those utilised by many other risk assessments in NHS hospitals (Chapter 6, Section 6.6.6). Completing this part of the measurement instrument could help in classifying dependent adults based on their risk of experiencing oral health deterioration, which could then help in assigning the optimal frequency of regular oral care with which they are provided. Regarding the second part of the measurement instrument, it might be advisable to complete it while performing regular oral care. This could improve efficiency, as regular oral care could provide the caregiver with the opportunity to look inside the dependent adult's mouth (Chapter 6, Section 6.6.6). This system could also improve efficiency because the frequency of the second part of the instrument would be determined by the risk of experiencing an oral health decline (Chapter 6, Section 6.6.6). While this frequency system is leaning toward the dynamic side, it may not cause a problem with completing the instrument consistently as the oral health measurement instrument has been incorporated into a larger care practice.

In the qualitative interview study, the ability to establish a feasible oral care plan based on the measurement instrument's outcomes was among the factors considered to be crucial for successful implementation (Chapter 6, Section 6.6.7). However, in this study, there was no agreement about how the oral care plan could or should be established. A group of the participants believed that rigid guidelines are needed to establish the appropriate oral care plan. They adopted this view to overcome the possible limitations in dental knowledge among the medical team. Other participants suggested adopting a more flexible approach by establishing the oral care plan through a multi-disciplinary team discussing the measurement instrument's outcomes. This approach was viewed to establish care plans that better suit different dependent patients' needs (Chapter 6, Section 6.6.7). However, it could be argued that without a dental professional within the multi-disciplinary team, the limited dental knowledge among the medical professionals may prevent the establishment of effective oral care plans. Thus, in such a situation, it might be necessary to establish predefined guidelines for oral care planning.

While the researchers who previously developed oral health measurement instruments have described guidelines for care planning based on the outcomes of their instruments, most of these guidelines only determined a threshold score by which the dependent adult needs to be referred to a dentist (Andersson *et al.*, 2002; Chalmers *et al.*, 2005; Konradsen *et al.*, 2014; Simpelaere *et al.*, 2016; Tsukada *et al.*, 2017; Klotz *et al.*, 2020). Nonetheless, participants in the qualitative interview study believed that oral care planning should be more comprehensive and efficient. Thus, they suggested that the actions in the oral care plan should be undertaken by nurses, a multi-disciplinary team or dental professionals based on the complexity of oral health problems identified by the measurement instrument (Chapter 6, Section 6.6.7).

Lastly, there are several steps that need to be undertaken once an oral health measurement instrument has been developed to improve its implementation success. For example, the participants in the qualitative interview study highlighted that the use of the measurement instrument should be incorporated into the NHS trust's policies and legislation (Chapter 6, Section 6.6.3). In addition, they suggest that efforts should be made to establish and strengthen the collaboration between the medical and dental teams. This could help in establishing more effective care plans, as well as facilitating the referral of dependent patients between them (Chapter 6, Section 6.6.7). Furthermore, the participants recommended that a pilot test should be undertaken to reveal and resolve any potential problems in the measurement instrument and other relevant aspects that were not anticipated before the implementation (Chapter 6, Section 6.6.3). Finally, continuous auditing was suggested to be conducted to assess whether the measurement instrument is being performed correctly after its implementation (Chapter 6, Section 6.6.3).

7.2 Recommendations for Future Research

While the development of a new oral health measurement instrument based on the findings of this PhD thesis could be done by a single researcher, utilising the co-design method during the development may offer many advantages. The co-design method could be defined as an iterative process in which a collaboration between relevant stakeholders and researchers is established to develop novel health services or interventions (e.g. an oral health measurement instrument) based on the best available scientific evidence, expert knowledge and experience and stakeholder involvement (Boyd *et al.*, 2012; Eyles *et al.*, 2016; O'Brien *et al.*, 2016). While this method requires extensive time, resources and effort to be undertaken (Bate and Robert, 2007), it could maximise the acceptability and potential effectiveness of the oral health measurement instrument (O'Brien *et al.*, 2016). It must be noted that this development process should not only focus on producing a sheet of paper that measures oral health; it should be made more comprehensive by establishing an integrated system that is capable of identifying and resolving oral health problems in dependent adults.

Once the new oral health measurement instrument is developed, a pilot testing of the instrument is needed to assess its content validity and feasibility (De Vet *et al.*, 2011, p. 57). Pilot testing is done by conducting a qualitative study (that utilises the cognitive interviews approach) with end-users who were not part of the developing team (Patrick *et al.*, 2011b). These interviews are semi-structured and are directed by a topic guide to establish evidence about the content validity of the instrument and how easily it could be used in the intended setting (Patrick *et al.*, 2011b).

The last step in the development of an oral health measurement instrument is known as field-testing (De Vet *et al.*, 2011, p. 65). In this step, a large-scale quantitative study is undertaken to assess the measurement properties of the instrument. To assess the reliability of the new instrument, the situation in which the study is conducted should mimic the situation in which the instrument will be used in the future (De Vet *et al.*, 2011, p. 124). For the validity and responsiveness part of the field-testing study, there is a need to formulate an *a priori* hypothesis about the expected performance of the instrument. Once data are collected and analysed, a decision to be made about accepting or refuting this hypothesis (De Vet *et al.*, 2011, p. 172).

Lastly, while the interpretability of the new measurement instrument will be mainly established during the co-design step, analysing data collected during the field-testing step could help in refining the accuracy of the clinical meanings assigned to the measurement instrument's quantitative scores. For example, this could be done by analysing the scores' distribution (i.e. mean and standard deviation), which could help in estimating how a change in score corresponds to a change in the construct (De Vet *et al.*, 2011, p. 230). In addition, a measurement error in the data could indicate the smallest detectable changes measured by the instrument (De Vet *et al.*, 2011, p. 242).

7.3 Conclusion

It is important to assess the oral health for dependent adults to guide their oral care planning. Findings form this thesis, however, indicate that developing a measurement instrument for this purpose may not be easy because of the stakeholders' different views. This thesis investigated the overall topic from different perspectives (i.e. dependent adults, service providers and previously developed oral health measurement instruments), and therefore its findings can contribute to the development of a new oral health measurement instrument that incorporate the stakeholders' different views and, thus, overcome any potential conflict. This thesis revealed that oral health in dependent adults is perceived to be a dynamic and multidimensional construct that consists of four distinctive domains: the intactness and cleanliness of oral structures; oral pain and discomfort; oral functions; and noticeable oral health aspects. In addition, it showed that service providers appreciate the importance of many factors, beside the measurement instrument itself, for successful implementation. These factors include the users of the instrument, the receivers of the instrument and the environment where the instrument used. Lastly, while the previously developed oral health measurement instruments, identified in this thesis, lack strong evidence to support their measurement properties, feasibility and interpretability, modified versions of the OHAT instrument or the THROAT instrument have the potential for future use once sufficiently tested and evaluated.

Appendices

Appendix A: Data extraction form for the qualitative evidence synthesis study

Data Extraction form		
	Data extracted by:	**Date:**

Study details		
Study Number:		
Author:	**Country:**	**Type** (interview/Focus groups/ other):
Publication year:		
Participants (dependent adults/ caregivers/ family member):		
Dependent adults' characteristics (to be completed even if the study only interviewed caregivers or family members)		
Cause of dependency (physical/mental/mixed/other):		
Age of dependent adults:		
Gender of dependent adults:		
Race/Ethnicity of dependent adults:		
Important disease characteristics (e.g. severity, status, duration):		
Caregivers' characteristics		
Caregivers status (professional health caregiver/ non-professional caregiver):		
Job title of caregivers:		
Speciality of caregivers:		
Race/Ethnicity of caregivers:		
Age of caregivers:		
Gender of caregivers:		
Family members' characteristics		
The relationship with dependent adult:		
Race/Ethnicity of family members:		
Age of family members:		
Gender of family members:		
Setting characteristics		
Care Setting:		
Study aim		
This papers research Question:		

Results:		
No.	Data (verbatim quotes from papers)	Code
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Appendix B: Characteristics of the excluded studies in the qualitative evidence synthesis study

Study	Reason for exclusion
MacEntee *et al.* (1987)	This was not a qualitative study, and therefore did not provide any qualitative data.
Miller and Rubinstein (1987)	The participants in this study were nursing students who did not meet the caregivers' criteria. In addition, data were collected using a survey. Furthermore, the topic of oral health in dependent adults was not discussed in this study.
Eadie and Schou (1992)	This study investigated the caregivers' attitude toward looking after the oral hygiene needs of dependent adults, and it did not investigate the oral health topic.
Karuza *et al.* (1992)	Even though the study utilised qualitative method, it did not provide any qualitative data in the result or discussion sections.
Nordenram *et al.* (1994)	This was not a qualitative study, and therefore did not provide any qualitative data.
Bryant *et al.* (1995)	This was not a qualitative study, and therefore did not provide any qualitative data.
Adams (1996)	This was not a qualitative study, and therefore did not provide any qualitative data.
Chalmers (1996)	This was not a qualitative study, and therefore did not provide any qualitative data.
Kayser-Jones (1996)	The study only explored strategies for conducting dental examination and did not explore the topic of oral health in dependent adults.
Gift *et al.* (1997)	The aim of this study was to discuss policy development and funding, and to assess the face validity of a questionnaire used in this study. Thus, this study did not meet the inclusion criteria of this review.
Frenkel (1999)	This study was about caregiver attitude toward oral care and did not discussed the topic of oral health in dependent adults.
Millwood and Heath (2000)	This study was about food choice of older people and not about oral health.
Öhrn *et al.* (2000)	This study was about barriers and facilitators to provide oral care. In addition, the population of interest in this study was cancer patients who did not meet the dependent adults' criteria.
Wårdh *et al.* (2000)	This study was about how the caregivers views the barriers to provide oral care for the patients and it was not about the topic of oral health in dependent adults.

Study	Reason for exclusion
Thorne *et al.* (2001)	This study investigated the effectiveness of oral care programme and it did not explore the topic of oral health in dependent adults. In addition, administrators (i.e. who do not meet the inclusion criteria as caregivers) have participated in this study and their findings were not separated from other participants.
Wårdh *et al.* (2002)	This study was about caregivers' attitude toward oral care and self-conceptions about oral care and it was not about oral health in dependent adults.
Hijii (2003)	This study investigated the nurses' practice and knowledge about oral care, as well as the barriers to perform oral care. In addition, it investigated the nurses' general knowledge about oral health, but not their views or perceptions about dependent adults' oral health.
Hilton and Simons (2003)	This study was only about dental visit and their barriers. In addition, no qualitative data were provided in the results or discussion sections.
McKelvey *et al.* (2003)	This study was only about the dental knowledge and the attitude of caregivers regarding oral care, and it was not about oral health in dependent adults.
Mofidi *et al.* (2003)	The participants in this study were students who gave their opinions about a learning experience. In addition, not all the population of interest in this study were dependent adults.
Wårdh *et al.* (2003)	This study was only about the experience of caregivers regarding providing oral care after introducing oral care aids.
Grant *et al.* (2004)	This study was only about the experience of oral health management, why the participants think it was successful and why it became successful.
Pelletier (2004)	The study was only about dysphagia and feeding and it was not related to the oral health in dependent adults.
MacEntee *et al.* (2005)	This study investigated the students' views about the impact of an educational course, and it did not investigate the topic of oral health in dependent adults.
De Visschere and Vanobbergen (2006)	This study only investigated dental care and it did not discuss the topic of oral health in dependent adults. In addition, not all the participants in this study were caregivers.
Preston *et al.* (2006)	This was a quantitative study, and it was only about oral care.
Andersson *et al.* (2007)	This study was about older people who were not necessary dependents.

Study	Reason for exclusion
Brondani *et al.* (2007)	This study was about older people who were not necessary dependents.
Hallberg and Klingberg (2007)	This study was only about oral care and dental care, and it was not about oral health. In addition, some of the participants were less than 18-year-old, while others were living independently.
Borreani *et al.* (2008)	Not all participants in this study were dependent adults. In addition, this study was only about barriers to dental care.
Brondani *et al.* (2008)	This study discussed the methods used in a previous study.
Young *et al.* (2008)	This study was only about staff knowledge regarding oral care. In addition, no qualitative data were provided in the results or discussion sections.
Corrêa Da Fonseca (2009)	This study was only about mobile dental services.
De Mello and Padilha (2009)	This study was only about the characteristics of oral care provided, and it did not investigate the topic of oral health in dependent adults.
Dharamsi *et al.* (2009)	This study was only about the impact of geriatric dental programme education on the level of knowledge, attitudes and practices regarding daily mouth care.
Borreani *et al.* (2010)	The study was about the utilisation of oral health care services by older people who were not necessary dependents.
Hopper and Szymkowiak (2010)	The study was only about how special care dentistry and general anaesthetic service were perceived by the patients and their caregivers. In addition, not all the participants were dependent adults.
Jin and Daly (2010)	A number of the participants in this study were living independently alone in their homes and thus were not considered as dependent adults.
Mello *et al.* (2010)	This study was only about oral care, and it did not investigate the topic of oral health in dependent adults. Some participants were not caregivers of dependent adults. In addition, no qualitative data were provided in the results or discussion sections.
Yeung and Chui (2010)	This study only investigated the factors affecting caregivers while providing oral care. It did not investigate the topic of oral health in dependent adults.
Owens *et al.* (2011)	This study investigated only the dependent adults' access to dental services, and it did not explore their oral health.

Study	Reason for exclusion
Scambler *et al.* (2011)	This study only investigated the dental care that is needed to be provided for disabled adults. In addition, some participants were not caregivers of dependent adults.
Sonde *et al.* (2011)	This study was only about caregivers' perceptions of oral care, and it did not investigate the topic of oral health in dependent adults.
Blinkhorn *et al.* (2012)	This was an implementation study with no qualitative data being reported.
Clovis *et al.* (2012)	This study was about dental policy development for vulnerable population who were not necessarily dependent adults.
Wårdh *et al.* (2012)	This was a quantitative study that only investigated the oral care for dependent adults without any exploration regarding the topic of oral health.
Alibhai (2013)	This study was not about oral health in dependent adults.
Compton *et al.* (2013)	This study only investigated the learning process without any exploration regarding the topic of oral health in dependent adults.
Wallace *et al.* (2013)	This study investigated the students' placement experience, and it did not investigate the topic of oral health in dependent adults.
Wilson *et al.* (2013)	This study focused on the communication strategies with dependent adults, but not their oral health. In addition, no qualitative data were provided.
Delinger *et al.* (2014)	This study was about the impact of ECP legislation on the access to dental services on people in underserved area who were not necessarily dependent adults.
Gardner *et al.* (2014)	This study was about dentist motivation to treat different groups of underserved population who were not necessarily dependent adults.
Hardgraves *et al.* (2014)	This study only investigated why dependent adults have limited access to dental care.
Hill *et al.* (2014)	This was a quantitative study.
Phadraig *et al.* (2014)	This study was about dental clinic attendance. In addition, not all the participants were dependent adults.
Taverna *et al.* (2014)	This study was only about the effect of autonomy on oral care without any exploration regarding the oral health of dependent adults.
Wallace *et al.* (2014)	This study was only about student transition from classroom to care facility.

Study	Reason for exclusion
Wårdh and Wikström (2014)	This study only investigated the impact of introducing oral care aids.
Bindal *et al.* (2015)	This was a quantitative study. In addition, not all the population of interest were dependent adults.
Compton and Kline (2015)	This study was only about the interaction between staff and dental hygiene students.
Horne *et al.* (2015)	This study was only about the barriers and facilitators for undertaking oral care for post-stroke patients and it was not about their oral health.
Lundqvist *et al.* (2015)	This study only analysed the mobile dental services from economic perspective with no qualitative data being provided.
McNally *et al.* (2015)	This study was only about the factors affecting the implementation of oral care programme.
Qu *et al.* (2015)	This study was only about oral care practice, attitude, education and knowledge among ICU staff. In addition, qualitative data in this study were analysed quantitatively.
Rashid-Kandvani *et al.* (2015)	This study only investigated the access to dental clinic of wheelchair users who were not necessarily dependent adults.
Scambler *et al.* (2015)	This study only investigated the barriers to access special care and general dental services and it did not investigate the topic of oral health in dependent adults.
Britton *et al.* (2016)	This study was only about the dental professionals' perception of barriers and enablers to providing oral care to residents in residential aged care facility and it was not about the residents' oral health.
Hearn and Slack-Smith (2016)	This study was only about exploring the views of aged-care facility staff on how to engage dental professionals in the provision of oral care for residents.
Hilton *et al.* (2016)	This study only investigated the implementation of oral care programme and it did not investigate the topic of oral health in dependent adults.
Adebayo *et al.* (2017)	This study was only about the perceptions of caregivers regarding the barriers to provide oral care, and it did not investigate the topic of oral health in dependent adults.
Alves *et al.* (2017)	The study only evaluated the oral care provided to disabled individuals. In addition, not all participants meet the criteria of dependent adults and caregivers.

Study	**Reason for exclusion**
Blaizot *et al.* (2017)	This study only investigated the dental ethical issues without exploring the topic of oral health in dependent adults.
Coker *et al.* (2017a)	This study only investigated how nurses provide oral care, how they decide on intervention and what factors influence their ability to provide oral care.
Coker *et al.* (2017b)	This study only reported the oral care provided by nurse to patient in hospital settings.
Huynh *et al.* (2017)	This study was only about the students' participation in conference and how it affects their awareness about oral health.
Kohli *et al.* (2017)	This was a quantitative study, and it was about the caregivers' attitude toward oral care.
Kvalheim *et al.* (2017)	No qualitative data were reported in this study.
Lees *et al.* (2017)	This study was about the expectations of community dental services, impact of dental treatment and feedback about the services. This study did not explore the topic of oral health in dependent adults.
Smith and Thomson (2017)	This was a quantitative study that only investigated the attitude toward oral care.
Villadsen and Sorensen (2017)	Most of the participants in this study lived in their own private residents, and therefore they were not dependent adults.
Yoon and Compton (2017)	This study was about learning experiences of students and it was not about the oral health of dependent adults.
Ahmad *et al.* (2018)	This was a quantitative study.
Crete *et al.* (2018)	Homebound patients were not necessarily dependent adults according the Medicare definition used in this study.
Eldh *et al.* (2018)	This study only investigated the oral care for dependent adults and not their oral health.
Horn *et al.* (2018)	Participants in this study were mixed of dependent and independent adults without distinguishing between their reports.
Maramaldi *et al.* (2018)	This study only investigated the oral care for dependent adults and not their oral health.
Sermsuti-Anuwat and Pongpanich (2018)	Participants in this study were not dependent adults.

Study	Reason for exclusion
Szabo *et al.* (2018)	This study only investigated the oral care for dependent adults and not their oral health.
Tynan *et al.* (2018)	This study only investigated the oral care for dependent adults and not their oral health.
Anderson *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.
Gopalakrishnan *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.
Jones *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.
Keboa *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.
Patel *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.
Scrine *et al.* (2019)	This study only investigated the oral care for dependent adults and not their oral health.

Appendix C: CERQual evidence profile for the qualitative evidence synthesis study

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.1. Intactness and cleanliness of anatomical oral structures (i.e. teeth, gingiva and mucosa) and dentures are criteria that are used to assess oral health in dependent adults.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as almost one fifth of the quotes contradict this finding where intactness and cleanliness of oral structures are not considered as a criterion. This contradiction could be explained by the level of oral health value dependent adults have, but because this was not clearly stated, coherence assessment was reduced.	No or very minor concerns regarding adequacy.	No or very minor concerns regarding relevance.	High confidence
1.2. Problems with teeth in dependent adults include being missing, decayed, fractured and mobile.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	High confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.3. Gingival problems in dependent adults include inflammation, swelling and bleeding.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as less than one fifth of the quotes do not strongly support the finding because it is not clear if inflammation and bleeding are related to the gingiva.	Minor concern regarding adequacy as only nine studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is mental-related. Also, studies were conducted in only five countries.	Moderate confidence
1.4. Other oral-related problems in dependent adults include dryness, thrush, ulcers and altered taste sensation.	Minor concerns regarding methodological limitations as "thrush" component is only supported by study where their participants volunteered to participate which may introduce potential biases.	No or very minor concerns regarding coherence.	Minor concern regarding adequacy as only nine studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related. Also, studies were conducted in only four countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.5. Denture problems in dependent adults include being ill-fitted, broken, trapping food or causing mucosal ulcers.	Minor concerns regarding methodological limitations as "broken denture" component is supported by one study where their participants volunteered to participate which may introduce potential biases.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only two studies support "broken denture" component and only 3 studies support "food impaction" component.	Moderate concerns regarding relevance as none of causes of dependency in the participants is physical-related.	Moderate confidence
1.6. Dentures when compared to natural teeth are viewed to be less functional, having poorer appearance and not contributing to quality of life like natural teeth.	No or very minor concerns regarding methodological limitations.	Minor concerns regarding coherence as in some quotes, it is not clear if dentures are less functional in general or only in comparison to natural teeth.	Moderate concerns regarding adequacy as only four studies discuss the contrast between natural teeth and dentures.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.7. Dependent adults prefer dentures over natural teeth only when they would like to maintain autonomy (because dentures are easier to maintain), as well as when their teeth deteriorate to a significant point.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as most of the quotes do not clearly support the part that dentures are preferred to maintain the autonomy.	Minor concerns regarding adequacy as only six studies discuss why dentures would be preferred.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence
1.8. Cleanliness of the mouth is a determinant of the anatomical oral structures' intactness.	Minor concern regarding methodological limitations as only two studies with no clear explanation of the relationship between researchers and participants are supporting aspects related to soft tissue intactness.	Minor concern regarding coherence as less than one fifth of the quote do not strongly support the finding.	Minor concern regarding adequacy as only seven studies support this finding.	Moderate concerns regarding relevance, as none of the causes of dependency in the participants is physical-related. Also, studies were conducted in only five countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.9. Type of diet is a determinant of natural teeth intactness.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Minor concern regarding adequacy as only five studies support this finding.	Moderate concerns regarding relevance as studies were conducted in only three countries.	High confidence
1.10. Some medications cause oral dryness, which deteriorates the intactness and cleanliness of natural teeth.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as more than half of the quotes do not clearly support the findings in regard to oral dryness and what aspects of oral health that are affected by the medications.	Moderate concerns regarding adequacy as only four studies support the finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related. Also, studies were conducted in only four countries.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.11. Oral pain and discomfort are criteria that are used to assess oral health in dependent adults.	No or very minor concerns regarding methodological limitations	Minor concern regarding coherence as less than one fifth of the quotes do not clearly support the finding and could have an alternative explanation where participants could define oral health only in regard to the integrity and cleanliness of oral structure and oral pain was only perceived as a consequence to oral health deterioration.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related. Also, no participants were recruited from hospital and studies were conducted in only seven countries.	High confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.12. Oral pain and discomfort are consequences of deterioration in the intactness and cleanliness of oral structures.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as almost one tenth of the quotes could have an alternative explanation where any denture would cause pain and discomfort when compared to natural teeth.	Moderate concerns regarding adequacy as only two studies support cleanliness as cause of pain.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related. Also, studies were conducted in only three countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.13. Oral functions (i.e. eating and speaking) are criteria that are used to assess oral health in dependent adults.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as almost half of the quotes do not clearly support the finding as they could have an alternative explanation where participants could defined oral health only in regard to the integrity and cleanliness of oral structure and oral functions are only perceived as a consequence to oral health deterioration.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.14. Oral dysfunction is a consequence of teeth loss and dentures deterioration.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as less than one fifth of the quotes contradict this finding where teeth and dentures status are not related to oral functions. Also, almost one third of the remaining quotes could have an alternative explanation where other aspects of oral health could influence the oral functions.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.15. Oral pain and discomfort lead to eating problems.	Minor concerns regarding methodological limitations as the study that support all aspects of the finding and shows the best methodological quality, their participants volunteered to participate that might introduce potential bias.	Moderate concerns regarding coherence as almost one third of quotes contradict this finding.	Serious concerns regarding adequacy as only four studies support the finding and data provided are superficial.	Serious concerns regarding relevance as only studies investigating oral health in age-related dependency from three countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.16. Oral health aspects that are noticeable by others (i.e. appearance and odour) are criteria that are used to assess oral health in dependent adults.	No or very minor concerns regarding methodological limitations	Moderate concerns regarding coherence as less than one tenth of the quotes contradict this finding and suggest that noticeable problems are not used in oral health assessment. Also, almost one third of the quotes could have an alternative explanation where participants could defined oral health only in regard to the integrity and cleanliness of oral structure and noticeable oral health problems are only perceived as a consequence to oral health deterioration.	No or very minor concerns regarding adequacy.	Minor concerns regarding relevance as no participants are from hospital setting.	High confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.17. The meanings of good oral appearance that dependent adults would like to have are: i) looking well-groomed and cared for, ii) having well aligned and white teeth, iii) having appearance that is natural and compatible with their age.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only five studies support the finding, and the richness of data is not adequate enough to know what are exactly meant by appearance compatible with age or well-groomed appearance. Also, data are not adequately rich enough to contrast between the three different meanings.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical related. Also, studies were conducted in only three countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
1.18. Problems in the intactness of natural teeth and dentures are determinant for creating poor oral appearance.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as almost one tenth of the quotes do not clearly support the finding as they may indicate that other aspects such as oral cleanliness could influence oral appearance.	Minor concern regarding adequacy as only eight studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence
1.19. Deterioration in oral cleanliness is determinant for creating noticeable bad oral odour.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Serious concerns regarding adequacy as only one study support the finding.	Serious concerns regarding relevance as the finding is only supported by a population with age-related dependency living in long-term care facilities in Canada.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.1. Intactness and cleanliness of oral structures alter the dependent adults' feeling about their wholeness and achievements, which impact on how dependent adults evaluate themselves (self-worth). Self-worth contributes to the sense of self-esteem, dignity and pride and subsequently overall quality of life.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as most of the quotes are about the effect of tooth loss on the quality of life with no discussion about the effect of the other oral structures on quality of life.	Moderate concerns regarding adequacy as only seven studies support the finding with richness of these studies are not adequately enough to investigate the relationships between dependent adults' feelings, their self-worth and quality of life.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.2. Ability to perform oral functions affects dependent adults' self-worth, which subsequently contributes to their quality of life.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as most of the quotes do not clearly and strongly support the finding.	Moderate concerns regarding adequacy as only five studies support the finding with richness of these studies are not adequately enough to investigate the relationships between dependent adults' self-worth and quality of life.	Moderate concerns regarding relevance as none of causes of dependency in the participants is physical-related and studies were conducted in only 4 countries.	Low confidence
2.3. Oral health problems that are noticeable by others affect dependent adults' self-worth, which subsequently contributes to their quality of life.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only two studies support the odour aspect of this finding and richness of data are not adequately enough to investigate the relationships between dependent adults' feelings, their self-worth and quality of life.	Moderate concerns regarding relevance as studies were conducted in only five countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.4. Performing self-daily oral care sustains the dependent adults' sense of being the same person as before dependency and the sense of autonomy, which results in a higher self-worth and subsequently better quality of life.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one of the quotes dose not strongly support the finding because it is not clear if deterioration in quality of life is related to oral care or oral health.	Moderate concerns regarding adequacy as only five studies support the finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only four countries.	Moderate confidence
2.5. Ability to perform oral functions during social interaction affects how dependent adults feel they are evaluated by others (social worth), which subsequently affects their quality of life.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as more than half of the quotes do not clearly support the effect of oral functions on social worth.	Serious concerns regarding adequacy as only three studies support the finding with richness of these studies are not adequately enough to investigate the relationships between dependent adults' social-worth and quality of life.	Serious concerns regarding relevance as the finding is only supported by population with age-related dependency who living in Netherlands and Canada.	Very low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.6. Oral health problems that are noticeable by others affect dependent adults’ social worth, which subsequently affects their quality of life.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as almost half of the quotes do not clearly support the effect of social worth on quality of life.	Moderate concerns regarding adequacy as only 11 studies support the finding with richness of these studies are not adequately enough to investigate the relationships between dependent adults' social-worth and quality of life.	Minor concerns regarding relevance as studies were conducted in only seven countries.	Moderate confidence
2.7. Performing daily oral care by caregivers for the dependent adults sustains their sense of being worthy and well-cared for, which results in a perceived higher social worth and subsequently better quality of life.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as almost all the quotes do not clearly support the effect of social worth aspect in this finding.	Serious concerns regarding adequacy as only one study support the finding.	Serious concerns regarding relevance as only age-related dependent adults in care homes in Netherlands support this finding.	Very low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.8. Dependent adults who are worrying about a reduction in their social worth due to oral health problems, avoid certain oral functions during social interaction or completely avoid social interaction with others.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only three studies support the relationship between social participation and quality of life.	Minor concerns regarding relevance as no participants recruited from hospital and studies were conducted in only six countries.	High confidence
2.9. Oral pain and discomfort directly impacts on dependent adults' quality of life.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as some of the quotes do not clearly support the finding as "discomfort" in those quotes might referring to loss of oral functions.	Moderate concerns regarding adequacy as only two studies support this finding.	Serious concerns regarding relevance as the finding is only supported from population with age-related dependency living in Netherlands and Canada.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.10. Ability to eat affects quality of life of dependent adults through the pleasure of eating food.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Minor concern regarding adequacy as only five studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only four countries.	High confidence
2.11. It is perceived that oral health status of dependent adults affects their general health.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only five countries.	High confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.12. Eating ability impacts on the nutritional status and subsequently general health of dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as less than one fifth of the quotes do not strongly support the finding because it is not clear if oral health is related to eating and subsequent problems.	Moderate concerns regarding adequacy as only 11 studies support the finding with richness of their data are not adequately enough to explore what aspect of nutritional status is affected and how it affects the general health.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only five countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.13. Poor cleanliness of oral structures is linked to aspiration pneumonia incidences.	Minor concern regarding methodological limitations as a study with no clear explanation of the relationship between researchers and participants and another study where their participants volunteered to participate which may introduce potential biases supports the finding.	Serious concerns regarding coherence as almost half of the quotes do not clearly specify oral cleanliness as the cause of aspiration pneumonia.	Moderate concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
2.14. Declined general health due to oral health deterioration could cause death.	Minor concern regarding methodological limitations as the relationship between researchers and participants in the best methodological study supporting all aspects of the finding is not clearly explained.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only three studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from three countries support the finding.	Moderate confidence
2.15. Oral pain and discomfort affect dependent adults' behaviours and ability to cooperate.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Serious concerns regarding adequacy as only four studies support the finding with richness of their data are not adequately enough to explore how pain affect mood and behaviours.	Moderate concerns regarding relevance as none of causes of dependency in the participants is physical-related and studies were conducted in only three countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
3.1. Maintaining the intactness and cleanliness of oral structures initiates the desire for daily oral care to be undertaken by/for dependent adults.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as less than one tenth of the quotes contradict the finding either because of the mental status of dependent adult, oral care is not effective, or because teeth deteriorated significantly and therefore oral care would not benefit the intactness. Also, more than half of quotes do not support the initiation part of this finding.	No or very minor concerns regarding adequacy.	Minor concerns regarding relevance as no participants recruited from hospital setting and studies were conducted in only eight countries.	Moderate confidence
3.2. Prevention of oral pain and discomfort initiates the desire for daily oral care to be undertaken by/for dependent adults.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Moderate concerns regarding adequacy as only four studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from three countries support the finding.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
3.3. Prevention of noticeable oral health problems initiates the desire for daily oral care to be undertaken by/for dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as almost one fifth of the quotes do not clearly support the finding regarding the initiation part.	Minor concerns regarding adequacy as only five studies support the finding.	Moderate concerns regarding relevance as none of causes of dependency in the participants is mental-related and studies were conducted in only four countries.	Moderate confidence
3.4. Deteriorated oral structures may act as a barrier preventing daily oral care to be performed by caregivers.	Minor concern regarding methodological limitations as one study with no clear explanation of the relationship between researchers and participants and another study where their participants volunteered to participate which may introduce potential biases are best studies supporting the finding.	Serious concerns regarding coherence as half of the quotes do not clearly support that structures need to be compromised to act as barrier.	Serious concerns regarding adequacy as only four studies support the finding with richness of their data are not adequately rich enough to explore what types of compromised structures may act as barrier.	Serious concerns regarding relevance as only age-related dependent adults from three countries support the finding.	Very low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
3.5. Deterioration in oral structures' intactness initiates the desire to seek professional dental care to restore them.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as almost one fifth of the quotes contradict the finding regarding compromised structures would not initiate desire for oral care. Also, many quotes do not clearly support that compromised structures would not initiate desire for oral care.	No or very minor concerns regarding adequacy.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
3.6. Oral pain and discomfort initiate the desire to seek professional dental care for relief.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as some quotes contradict the finding and suggest pain would not initiate dental treatment. Also, some quotes do not clearly support the finding regarding the initiation of dental treatment consequently to pain.	Minor concern regarding adequacy as only nine studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
3.7. Oral dysfunctions initiate the desire to seek professional dental care for oral functions' rehabilitation.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as almost all the quotes are only related to eating and not other oral functions. Also, one of the quotes suggest that oral dysfunction do not initiate oral care. Also, one quote dose not clearly support the "desire initiation" part.	Moderate concerns regarding adequacy as only four studies support the finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only four countries.	Low confidence
3.8. Noticeable oral health problems initiate the desire to seek professional dental care to be fixed.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as all the quotes do not support the odour part of noticeable problems.	Minor concerns regarding adequacy as only five studies support the finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only four countries.	Moderate confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.1. Deterioration in general health reduces the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one tenth of the quotes contradict this finding and suggest that deterioration in general health do not reduces value.	Minor concern regarding adequacy as only five studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from three countries support this finding.	Moderate confidence
4.2. Dependent adults prefer to focus their limited energy on serious general health conditions rather than on oral health, which could result in a reduction in the value of oral health.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as most of the quotes do not clearly support the effect of this factor on overall value but only on action.	Serious concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from one country support this finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.3. Believing that deterioration in oral health is an inevitable consequence of advancement in age or deterioration in general health reduces the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as almost one third of the quotes do not clearly support that the dependent adults believe affect the value.	Moderate concerns regarding adequacy as only five studies support the finding with richness of their data are not adequately enough to explore why these believes reduces oral health value.	Serious concerns regarding relevance as only age-related dependent adults from three countries support this finding.	Low confidence
4.4. Anticipating death in the near future reduces the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as almost half of the quotes do not clearly support the findings either regarding the effect of age on overall oral health value or if advancement in age is related to anticipating death.	Serious concerns regarding adequacy as only three studies support the finding with richness of their data are not adequately rich enough to explore why anticipating death reduces oral health value.	Serious concerns regarding relevance as only age-related dependent adults from three countries support the finding.	Very low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.5. Some dependent adults with deterioration in their general health place more value on oral health to remain the same as before health decline by keeping the same level of oral health.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Serious concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from one country support the finding.	Low confidence
4.6. Deterioration in quality of life reduces the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one quote do not clearly support the finding.	Serious concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.7. Inability to perform or receive daily oral care and unavailability of access to professional dental care reduces the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as almost one fifth of the quotes contradict the finding and suggest that ability and availability do not affect value.	Serious concerns regarding adequacy as only four studies support the finding with richness of their data are not adequately rich enough to explore why ability and availability affect value.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence
4.8. Oral health of dependent adults' peers influences what they consider as optimal oral health and subsequently affects the value they place on oral health.	No or very minor concerns regarding methodological limitations.	Moderate concerns regarding coherence as almost one third of the quotes contradict the finding and suggest that peers' oral health is not related to the value.	Serious concerns regarding adequacy as only three studies support the finding with richness of their data are not adequately rich enough to rigorously explore why peers' oral health affect value.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.9. Original beliefs and attitudes towards oral health influence the value given to oral health by dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one quote do not clearly support the finding.	Serious concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence
4.10. The amount of value placed by dependent adults on oral health affects how they evaluate their oral health (i.e. which criteria are used to define and evaluate their oral health).	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Minor concern regarding adequacy as only five studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only three countries.	High confidence
4.11. Oral structures lose their importance and value for dependent adults before the other three domains of oral health (i.e. pain, functions and noticeability).	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as one quote contradict the finding and most of the other quotes do not clearly support the finding.	Moderate concerns regarding adequacy as only three studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.12. Oral pain and discomfort is the last domain of oral health that lose its importance and value in dependent adults.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one quote contradict the finding and suggest noticeable problems are more important than pain. Also, another quote is not clear if it refers to pain.	Moderate concerns regarding adequacy as only four studies support the finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only three countries.	Moderate confidence
4.13. Noticeable oral health aspects lose their importance and value for dependent adults before oral functions.	No or very minor concerns regarding methodological limitations.	No or very minor concerns regarding coherence.	Serious concerns regarding adequacy as only two studies support the finding.	Serious concerns regarding relevance as only age-related male dependent adults from two countries support the finding.	Low confidence

Finding	Methodological limitations	Coherence	Adequacy	Relevance	Confidence assessment
4.14. The amount of value placed by dependent adults on oral health affects the degree of decline in their quality of life that results from oral health deterioration.	No or very minor concerns regarding methodological limitations.	Serious concerns regarding coherence as most quotes do not clearly support the finding because it is not clear if participants only loss the interest or oral health do not impact quality of life anymore.	Moderate concerns regarding adequacy as only three studies support the finding.	Serious concerns regarding relevance as only age-related dependent adults from two countries support the finding.	Low confidence
4.15. The amount of value placed by dependent adults on oral health affects their desire to seek professional dental care and the desire to receive or undertake daily oral care.	No or very minor concerns regarding methodological limitations.	Minor concern regarding coherence as one tenth of the quotes do not clearly support the finding regarding the effect of value on oral care.	Minor concern regarding adequacy as only nine studies support this finding.	Moderate concerns regarding relevance as none of the causes of dependency in the participants is physical-related and studies were conducted in only five countries.	Moderate confidence

Appendix D: MEDLINE search strategy to identify relevant studies in the quantitative systematic review study

1	Oral Health/ or Stomatognathic Diseases/ or Jaw Diseases/ or exp jaw, edentulous/ or mandibular diseases/ or maxillary diseases/ or Mouth Diseases/ or Burning Mouth Syndrome/ or Candidiasis, Oral/ or Lip Diseases/ or Oral Ulcer/ or Periodontal Diseases/ or Salivary Gland Diseases/ or Stomatitis/ or Tongue Diseases/ or exp Temporomandibular Joint Disorders/ or Tooth Diseases/ or exp dental deposits/ or dentin sensitivity/ or focal infection, dental/ or exp mouth, edentulous/ or exp tooth demineralization/ or tooth loss/ or toothache/ or exp Dental Health Services/ or Dentistry/ or Dental Research/ or Evidence-Based Dentistry/ or Geriatric Dentistry/ or Preventive Dentistry/ or exp Oral Hygiene/ or Public Health Dentistry/ or exp Dental Health Surveys/ or Community Dentistry/ or (Oral* adj1 health*).mp. or (Oral* adj1 hygiene*).mp. or (Oral* adj1 disease*).mp. or (dent* adj1 disease*).mp. or (oral* adj2 care*).mp. or (mouth* adj2 care*).mp. or (t??th* adj2 care*).mp. or (T??th adj1 brush*).mp. or exp Facial Pain/ or (Orofacial adj2 pain).mp. or (Dent* adj2 pain).mp or (T??th adj2 pain).mp. or (oral* adj2 pain).mp or (mouth* adj2 pain).mp. or (facial* adj2 pain).mp. or TMD.mp. or (Temporomandibular adj1 disorder).mp. or T??thache.mp. or (Dental* adj1 care*).mp. or exp Jaw Neoplasms/ or Mucositis/ or Gingival Diseases/ or Periodontitis/ or Xerostomia/ or dental pulp diseases/ or Diagnosis, Oral/ or Photography, Dental/ or Cheilitis/ or Lip Neoplasms/ or Mouth Neoplasms/ or Gingival Neoplasms/ or Tongue Neoplasms/ or Stomatitis, Denture/ or tooth wear/ or tooth injuries/ or Tooth Fractures/ or (oral* adj1 ass*).mp. or (dent* adj1 ass*).mp.
2	Frail Elderly/ or Multiple Chronic Conditions/ or Catastrophic Illness/ or exp basal ganglia diseases/ or exp brain damage, chronic/ or exp brain death/ or exp brain diseases, metabolic/ or exp brain injuries/ or exp cerebellar diseases/ or exp cerebrovascular disorders/ or exp dementia/ or exp "diffuse cerebral sclerosis of schilder"/ or exp encephalitis/ or exp hypoxia, brain/ or exp leukoencephalopathies/ or exp neuroaxonal dystrophies/ or exp sepsis-associated encephalopathy/ or exp thalamic diseases/ or Disabled Persons/ or Amputees/ or Mentally Disabled Persons/ or Mentally Ill Persons/ or Motor Disorders/ or Intellectual Disability/ or Motor Skills Disorders/ or Developmental Disabilities/ or Neurocognitive Disorders/ or Consciousness Disorders/ or exp Coma/ or Persistent Vegetative State/ or Stupor/ or exp Cognition Disorders/ or Terminally Ill/ or Vulnerable Populations/ or Intensive Care Units/ or Burn Units/ or Coronary Care Units/ or Respiratory Care Units/ or exp Residential Facilities/ or Caregivers/ or Caregivers/ or Health Services for Persons with Disabilities/ or Critical Care Nursing/ or Geriatric Nursing/ or Neuroscience Nursing/ or Rehabilitation Nursing/ or Palliative Care Nursing/ or exp Critical Care/ or exp Institutionalization/ or Life Support Care/ or Long-Term Care/ or Subacute Care/ or exp Terminal Care/ or Palliative Care/ or Activities of Daily Living/ or Self care/ or Geriatric Assessment/ or (Dependent adj1 adult*).mp. or ICU.mp. or Disable*.mp. or ADL*.mp. or CAREGIVER*.mp. or Stroke*.mp. or Dementia*.mp. or Dementia*.mp. or Adult Day Care Centers/ or Inpatients/

3	(instrumentation or methods).sh. or (Validation Studies or Comparative Study).pt. or exp Psychometrics/ or psychometr*.ti,ab. or (clinimetr* or clinometr*).tw. or exp "Outcome Assessment (Health Care)"/ or outcome measure*.tw. or exp Observer Variation/ or observer variation.ti,ab. or exp Health Status Indicators/ or exp "Reproducibility of Results"/ or reproducib*.ti,ab. or exp Discriminant Analysis/ or (reliab* or unreliab* or valid* or coefficient or homogeneity or homogeneous or "internal consistency").ti,ab. or (cronbach* and (alpha or alphas)).ti,ab. or (item and (correlation* or selection* or reduction*)).ti,ab. or (agreement or precision or imprecision or "precise values" or test-retest).ti,ab. or (test and retest).ti,ab. or (reliab* and (test or retest)).ti,ab. or (stability or interrater or inter-rater or intrarater or intra-rater or intertester or inter tester or intratester or intra-tester or interobserver or inter-observer or intraobserver or intra-observer or intertechnician or inter-technician or intratechnician or intra technician or interexaminer or inter-examiner or intraexaminer or intra-examiner or interassay or inter-assay or intraassay or intra-assay or interindividual or inter individual or intraindividual or intra-individual or interparticipant or inter-participant or intraparticipant or intra-participant or kappa or kappa's or kappas or repeatab*).ti,ab. or ((replicab* or repeated) and (measure or measures or findings or result or results or test or tests)).ti,ab. or (generaliza* or generalisa* or concordance).ti,ab. or (intraclass and correlation*).ti,ab. or (discriminative or "known group" or factor analysis or factor analyses or dimension* or subscale*).ti,ab. or (multitrait and scaling and (analysis or analyses)).ti,ab or (item discriminant or interscale correlation* or error or errors or "individual variability").ti,ab. or (variability and (analysis or values)).ti,ab. or (uncertainty and (measurement or measuring)).ti,ab. or ("standard error of measurement" or sensitiv* or responsive*).ti,ab. or ((minimal or minimally or clinical or clinically) and (important or significant or detectable) and (change or difference)).ti,ab. or (small* and (real or detectable) and (change or difference)).ti,ab. or (meaningful change or "ceiling effect" or "floor effect" or "Item response model" or IRT or Rasch or "Differential item functioning" or DIF or "computer adaptive testing" or "item bank" or "cross-cultural equivalence").ti,ab.
4	1 and 2 and 3
5	(child* not adult*).mp.
6	limit 5 to "all child (0 to 18 years)"
7	4 not 6
8	limit 7 to English language

Appendix E: Criteria for good measurement properties used in the quantitative systematic review study

Measurement property	Rating	Criteria
Content validity	+	The relevance rating is +, the comprehensive rating is + and the comprehensibility rating is +
	?	Inconsistent ratings
	–	The relevance rating is –, the comprehensive rating is – and the comprehensibility rating is –
Internal consistency	+	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) ≥ 0.70 for each unidimensional scale or subscale
	?	Criteria for at least low evidence for sufficient structural validity was not met
	–	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) < 0.70 for each unidimensional scale or subscale
Reliability	+	ICC or Kappa ≥ 0.70
	?	ICC or Kappa not reported
	–	ICC or Kappa < 0.70
Measurement error	+	SDC or LoA < MIC
	?	MIC not defined
	–	SDC or LoA > MIC
Construct validity	+	The result is in accordance with the hypothesis OR AUC ≥ 0.70
	?	No hypothesis defined (by the research team or the review team)
	–	The result is not in accordance with the hypothesis OR AUC < 0.70

Measurement property	Rating	Criteria
Structural validity	**+**	**CTT:** CFA: CFI or TLI >0.95 OR RMSEA <0.06 OR SRMR <0.082 **IRT/Rasch:** No violation of unidimensionality: CFI or TLI >0.95 OR RMSEA <0.06 OR SRMR <0.08 *AND* no violation of local independence: residual correlations, among the items after controlling for the dominant factor < 0.20 OR Q3s < 0.37 *AND* no violation of monotonicity: adequate looking graphs OR item scalability >0.30 *AND* adequate model fit: IRT: χ2 >0.01 Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z-standardized values > –2 and < 2
	?	CTT: Not all information for ‘+’ reported IRT/Rasch: Model fit not reported
	–	Criteria for ‘+’ not met
Cross-cultural validity	**+**	No important differences found between group factors (such as age, gender, language) in multiple group factor analysis OR no important DIF for group factors (McFadden's R^2 < 0.02)
	?	No multiple group factor analysis OR DIF analysis performed
	–	Important differences between group factors OR DIF were found
Criterion validity	**+**	Correlation with gold standard ≥ 0.70 OR AUC ≥ 0.70
	?	Not all information for ‘+’ reported
	–	Correlation with gold standard < 0.70 OR AUC < 0.70
Responsiveness	**+**	The result is in accordance with the hypothesis OR AUC ≥ 0.70
	?	No hypothesis defined (by the research team or the review team)
	–	The result is not in accordance with the hypothesis OR AUC < 0.70

- **Abbreviations used in the table:**
    - '+' = sufficient, '–' = insufficient, '?' = indeterminate
    - AUC = Area Under the Curve, CFA = Confirmatory Factor Analysis, CFI = Comparative Fit Index, CTT = Classical Test Theory, DIF = Differential Item Functioning, ICC = Intraclass Correlation Coefficient, IRT = Item Response Theory, LoA = Limits of Agreement, MIC = Minimal Important Change, RMSEA: Root Mean Square Error of Approximation, SEM = Standard Error of Measurement, SDC = Smallest Detectable Change, SRMR: Standardized Root Mean Residuals, TLI = Tucker-Lewis index

- **Generic hypotheses that were used to evaluate construct validity and responsiveness** (Prinsen *et al.*, 2018):
    - Correlations with (changes in) instruments measuring similar constructs should be ≥0.50
    - Correlations with (changes in) instruments measuring related, but dissimilar, constructs should be lower, i.e. 0.30–0.50
    - Correlations with (changes in) instruments measuring unrelated constructs should be <0.30
    - Meaningful changes between relevant (sub)groups (e.g. patients with expected high vs. low levels of the construct of interest)

These criteria were adapted from Terwee *et al.* (2007) and Terwee *et al.* (2018).

Appendix F: Characteristics of the excluded studies in the quantitative systematic review study

Study	Reason for exclusion
(Rise, 1979)	Not all the participants in this study were dependent adults.
(Harvey *et al.*, 1980)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Schweiger and Lang, 1981)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Mehrotra *et al.*, 1982)	Not all the participants in this study were dependent adults.
(AxÉLl *et al.*, 1985)	Not all the participants in this study were dependent adults.
(Gray *et al.*, 1986)	Not all the participants in this study were dependent adults.
(Rosenberg *et al.*, 1988)	Not all the participants in this study were dependent adults.
(Atchison and Dolan, 1990)	Not all the participants in this study were dependent adults.
(Locker and Slade, 1993)	Not all the participants in this study were dependent adults.
(Doherty *et al.*, 1994)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Felder *et al.*, 1994)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Burke and Wilson, 1995)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Kayser-Jones and Schell, 1995)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Arvidson-Bufano, 1996)	The measurement instrument in this study did not measure oral health or orofacial pain.

Study	Reason for exclusion
(Blank, 1996)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Bush *et al.*, 1996)	Not all the participants in this study were dependent adults.
(Doherty *et al.*, 1996)	Not all the participants in this study were dependent adults.
(Locker and Jokovic, 1996)	Not all the participants in this study were dependent adults.
(Dolan, 1997)	Not all the participants in this study were dependent adults.
(Fries *et al.*, 1997)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Kressin *et al.*, 1997)	Not all the participants in this study were dependent adults.
(Thai, 1997)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Edmonds *et al.*, 1998)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Calabrese, 1999)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Lin, 1999)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(MacEntee and Wyatt, 1999)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Jones *et al.*, 2000)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.

Study	**Reason for exclusion**
(Nederfors *et al.*, 2000)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Bauer, 2001)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Locker *et al.*, 2001)	Not all the participants in this study were dependent adults.
(Robinson *et al.*, 2001)	Not all the participants in this study are dependent adults.
(Nordenram and Ljunggren, 2002)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Watkins, 2002)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Wong *et al.*, 2002a)	Not all the participants in this study were dependent adults.
(Wong *et al.*, 2002b)	Not all the participants in this study were dependent adults.
(Andersson *et al.*, 2003)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Eisbruch *et al.*, 2003)	Not all the participants in this study were dependent adults.
(Andersson, 2004)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Head *et al.*, 2004)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Locker *et al.*, 2004)	Not all the participants in this study were dependent adults.
(Olson *et al.*, 2004)	Not all the participants in this study were dependent adults.

Study	Reason for exclusion
(Pace-Balzan *et al.*, 2004)	Not all the participants in this study were dependent adults.
(Aggarwal *et al.*, 2005)	Not all the participants in this study were dependent adults.
(Chalmers and Pearson, 2005)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Gerdin *et al.*, 2005)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Hanneman and Gusick, 2005)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Locker and Gibson, 2005)	Not all the participants in this study were dependent adults.
(Ruiz-Medina *et al.*, 2005)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Naito *et al.*, 2006)	Not all the participants in this study were dependent adults.
(Othman *et al.*, 2006)	Not all the participants in this study were dependent adults.
(Brondani, 2007)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Brondani and MacEntee, 2007)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Chia-Hui Chen *et al.*, 2007)	Not all the participants in this study were dependent adults.
(Husebo *et al.*, 2007)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Klimon, 2007)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Mouthon *et al.*, 2007)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Atieh, 2008)	Not all the participants in this study were dependent adults.

Study	Reason for exclusion
(Daradkeh and Khader, 2008)	Not all the participants in this study were dependent adults.
(Ergül and Akar, 2008)	Not all the participants in this study were dependent adults.
(Hassel *et al.*, 2008)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Heyes and Robinson, 2008)	Not all the participants in this study were dependent adults.
(Jensen *et al.*, 2008)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Jung *et al.*, 2008)	Not all the participants in this study were dependent adults.
(Paulsson *et al.*, 2008)	Not all the participants in this study were dependent adults.
(Zhu *et al.*, 2008)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Jablonski *et al.*, 2009)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Husebo *et al.*, 2009)	The measurement instrument in this study did not measure oral health or orofacial pain.
(McGrath *et al.*, 2009)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Turner *et al.*, 2009)	The measurement instrument in this study does not measure oral health or orofacial pain.
(Almeida *et al.*, 2010)	The measurement instrument in this study did not measure oral health or orofacial pain
(Åstrøm *et al.*, 2010)	Not all the participants in this study were dependent adults.

Study	Reason for exclusion
(Bateman *et al.*, 2010)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Buunk-Werkhoven *et al.*, 2010)	Not all the participants in this study were dependent adults.
(Franchignoni *et al.*, 2010)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Hassel *et al.*, 2010)	Not all the participants in this study were dependent adults.
(Husebo *et al.*, 2010)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Katz *et al.*, 2010)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(KnÖÖs and Östman, 2010)	Not all the participants in this study were dependent adults.
(Murariu *et al.*, 2010)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Sánchez-García *et al.*, 2010)	Not all the participants in this study were dependent adults.
(Ames *et al.*, 2011)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Burgess *et al.*, 2011)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Hamada *et al.*, 2011)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Sheu *et al.*, 2011)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Wang and Ling, 2011)	Not all the participants in this study were dependent adults.

Study	Reason for exclusion
(Castrejón-Pérez and Borges-Yáñez, 2012)	Not all the participants in this study were dependent adults.
(de Lima Saintrain and Vieira, 2012)	Not all the participants in this study were dependent adults.
(de Mello *et al.*, 2012)	The study was published in language other than English.
(El Osta *et al.*, 2012)	Not all the participants in this study were dependent adults.
(Erić *et al.*, 2012)	Not all the participants in this study were dependent adults.
(Ikebe *et al.*, 2012)	Not all the participants in this study were dependent adults.
(Kikutani *et al.*, 2012)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Machado *et al.*, 2012)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Bonanato *et al.*, 2013)	Not all the participants in this study were dependent adults.
(Lawal *et al.*, 2013)	Not all the participants in this study were dependent adults.
(Marshall *et al.*, 2013)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Milani *et al.*, 2013)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Prendergast *et al.*, 2013)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Schouffoer *et al.*, 2013)	Not all the participants in this study were dependent adults.
(Viana *et al.*, 2013)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.

Study	**Reason for exclusion**
(Brody *et al.*, 2014)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Galczyńska-Rusin *et al.*, 2014)	Not all the participants in this study were dependent adults.
(Husebo *et al.*, 2014)	The measurement instrument in this study did not measure oral health or orofacial pain.
(La Touche *et al.*, 2014)	Not all the participants in this study were dependent adults.
(Ribeiro *et al.*, 2014)	Not all the participants in this study were dependent adults.
(Santucci *et al.*, 2014)	Not all the participants in this study were dependent adults.
(Campos *et al.*, 2015)	Not all the participants in this study were dependent adults.
(Nam *et al.*, 2015)	Not all the participants in this study were dependent adults.
(Rijkenberg *et al.*, 2015)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Campos *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Chipps *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Ellis-Smith *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Hoben *et al.*, 2016)	Not all the participants in this study were dependent adults.
(Johansson *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.

Study	Reason for exclusion
(Jones *et al.*, 2016)	Not all the participants in this study were dependent adults.
(Kothari *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Lautenbacher and Kunz, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Mehta *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Nguh, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Niesten *et al.*, 2016b)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Niesten *et al.*, 2016a)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Pradhan *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Rekhi *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Rezaei *et al.*, 2016)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.

Study	Reason for exclusion
(Shekhawat *et al.*, 2016)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Steinmassl *et al.*, 2016)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Chen *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Denis *et al.*, 2017a)	Not all the participants in this study were dependent adults.
(Denis *et al.*, 2017b)	Not all the participants in this study were dependent adults.
(Dugashvili *et al.*, 2017)	Not all the participants in this study were dependent adults.
(Fjeld *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Husebo, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Lee *et al.*, 2017b)	The study was published in language other than English.
(León *et al.*, 2017)	Not all the participants in this study were dependent adults.
(Marchini *et al.*, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Miremadi *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Moon *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Mori *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Neblett *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.

Study	Reason for exclusion
(Petrović *et al.*, 2017)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Queyroux *et al.*, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Rijkenberg *et al.*, 2017)	The measurement instrument in this study did not measure oral health or orofacial pain.
(van Kooten *et al.*, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(van Kooten *et al.*, 2017)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Wöstmann *et al.*, 2017)	Not all the participants in this study were dependent adults.
(Chen and Liu, 2018)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Frederic *et al.*, 2018)	Not all the participants in this study were dependent adults.
(Kim and Park, 2018)	The study was published in language other than English.
(Kossioni *et al.*, 2018)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Lautenbacher *et al.*, 2018)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Noguchi *et al.*, 2018)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Osman *et al.*, 2018)	Not all the participants in this study were dependent adults.

Study	**Reason for exclusion**
(Prendergast and Hinkle, 2018)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Rekhi *et al.*, 2018)	This study did not describe the development of a new measurement instrument or evaluation of measurement properties, interpretability or feasibility of an existing instrument.
(Agrawal *et al.*, 2019)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Aoki *et al.*, 2019)	The measurement instrument in this study was not originally developed to measure oral health or orofacial pain in dependent adults and it was not revised in this study to be used in measuring oral health or orofacial pain in dependent adults.
(Cheng *et al.*, 2019)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Laurence *et al.*, 2019)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Nakagawa and Matsuo, 2019)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Waza *et al.*, 2019)	The measurement instrument in this study did not measure oral health or orofacial pain.
(Fleming *et al.*, 2020)	The measurement instrument in this study did not measure oral health or orofacial pain.

Appendix G: Newcastle University's ethical approval for the qualitative study

Newcastle University

Faculty of Medical Sciences
Newcastle University
Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH

26 October 2018

Fahad BaHammam
Institute of Health & Society

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Fahad,

Title: Investigating orofacial pain and oral health assessment for care planning of patients after stroke
Application No: 1609/6994/2018
Start date to end date: 01 October 2018 to 20 December 2019

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **1609/6994/2018.** If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

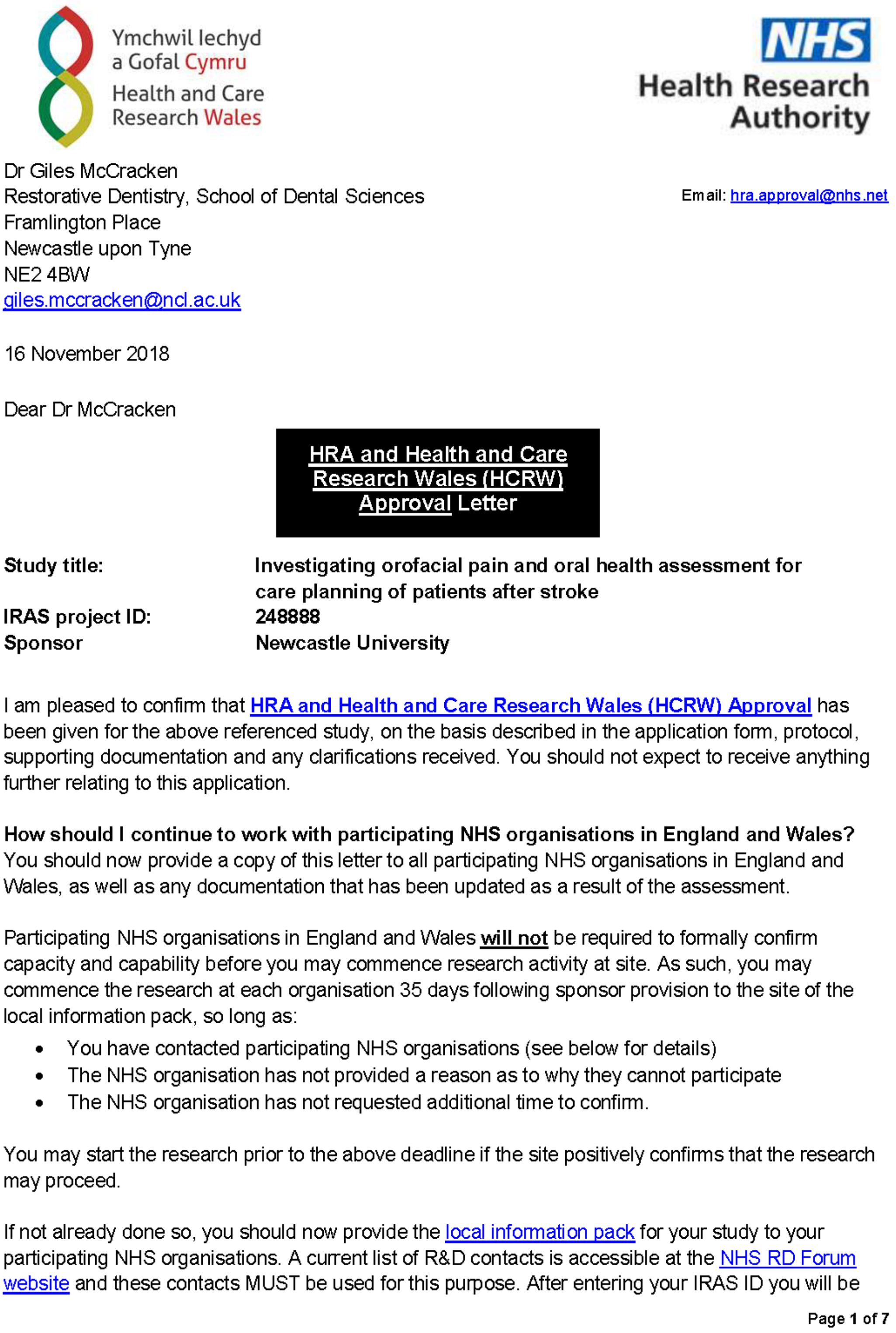
M. Holbrough

Marjorie Holbrough
On behalf of Faculty Ethics Committee

cc.
Professor Daniel Nettle, Chair of FMS Ethics Committee
Mrs Kay Howes, Research Manager

*Please refer to the latest guidance available on the internal Newcastle web-site.

Appendix H: The Health Research Authority (HRA) Approval for the qualitative study



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Giles McCracken
Restorative Dentistry, School of Dental Sciences
Framlington Place
Newcastle upon Tyne
NE2 4BW
giles.mccracken@ncl.ac.uk

Email: hra.approval@nhs.net

16 November 2018

Dear Dr McCracken

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Investigating orofacial pain and oral health assessment for care planning of patients after stroke**
IRAS project ID:	**248888**
Sponsor	**Newcastle University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales **will not** be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation 35 days following sponsor provision to the site of the local information pack, so long as:

- You have contacted participating NHS organisations (see below for details)
- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: **House45**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Kay Howes
Tel: 0191 208 7460
Email: kay.howes@ncl.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **248888**. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Kay Howes, Newcastle University [Sponsor Contact]*
kay.howes@ncl.ac.uk
Ms Michelle Ahmed, Newcastle-Upon-Tyne Hospitals NHS Foundation Trust [Lead NHS R&D Contact]
michelle.ahmed@nuth.nhs.uk

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Caldicott correspondence]	1	20 September 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Zurich insurance]	1	01 August 2018
HRA Schedule of Events	1	24 October 2018
HRA Statement of Activities	1	24 October 2018
Interview schedules or topic guides for participants [Topic guide]	3	20 August 2018
IRAS Application Form [IRAS_Form_12102018]		12 October 2018
IRAS Application Form XML file [IRAS_Form_12102018]		12 October 2018
IRAS Checklist XML [Checklist_12102018]		12 October 2018
Letter from sponsor [Sponsorship letter]	1	14 August 2018
Participant consent form [Consent Form]	2	26 October 2018
Participant information sheet (PIS)	5	15 November 2018
Referee's report or other scientific critique report [Project-Approval]	1	11 May 2017
Research protocol or project proposal [Protocol]	1	20 August 2018
Summary CV for Chief Investigator (CI) [CV - McCracken]		
Summary CV for student [CV - Bahammam]	2	10 October 2018
Summary CV for supervisor (student research) [CV - McCracken]		

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	Filter Question 4b of IRAS has not been completed however, the study is involving NHS staff as participants.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study, and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this letter.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	The study has not received any external funding and as such no funding will be provided to the participating NHS sites to run the study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant has confirmed no identifiable data will be sent to the professional transcription company, and as such a confidentiality agreement is not in place between them and the sponsor.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
There is one site type participating in the study. All research activities taking place at the participating NHS sites is the same, as detailed in the study protocol and supporting documentation. **Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.**

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

No Local Collaborator/Principal Investigator is required at participating NHS sites, although a local contact is required to identify potential participants and facilitate the booking of meeting rooms for the face to face interviews to take place.

Training – No training will be provided to the research team, however the sponsor expects researchers to have undergone GCP training.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

No access arrangements are required for staff interviews being undertaken in non-clinical setting.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.
- The applicant has confirmed a local member of staff (Professor Helen Rodgers at Newcastle upon Tyne Hospitals NHS FT and Professor Craig Smith at Salford Royal NHS FT) has agreed to facilitate the boking of meeting rooms for the interviews. Audio recording devices will be provided by the research team.

Appendix I: Participant information sheet for the qualitative study

Newcastle University
Institute of Health & Society

IRAS ID: 248888

Investigating orofacial pain and oral health assessment for care planning of patients after stroke

Information Sheet

We would like to invite you to take part in our research study. Before you decide, we would like you to understand our research topic and why the research is being done and what it would involve for you. This invitation is to invite you for an interview to share your opinion and perspectives about orofacial pain and oral health in patients after stroke. This research will form a part of a PhD thesis titled "Investigating orofacial pain and oral health assessment measures for care planning of dependent adults".

Please read the following information carefully and contact us if there is anything that requires further explanation before you decide whether or not to take part. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the study about?

The main aim of this study is to explore and understand orofacial pain and oral health assessment for patients after stroke.

Why have I been invited?

We are looking for a wide range of stroke service providers with different levels of clinical expertise among different dental and medical specialities who provide care for patients after stroke. There may be more than twenty participants to interview in this study. We think you fit the criteria outlined above.

What do I have to do?

You will be asked about your perception in relation to orofacial pain and oral health of patients after stroke and any barriers that may prevent assessment of orofacial pain and oral health. In addition, you will be asked to look at previously developed assessment instrument(s) of orofacial pain and oral health and then to evaluate its/their relevance, comprehensiveness, comprehensibility, acceptability and feasibility for patients after stroke.

Do I have to take part?

No, absolutely not. The choice is entirely up to you and, even if you decide to take part and then later wish to drop out, you may do so without giving any reason.

Expenses and payments:

We appreciate your time is valuable and therefore offer you gift vouchers/cards to the value of £20 for completing the study. Any reasonable travel expenses will be reimbursed.

Version 5 15/11/2018

Who is the Sponsor?

Newcastle University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Newcastle University will keep identifiable information about you for 5 years after the study has finished.

Indemnity

We consider that this study poses minimal risk for participants and we do not anticipate any adverse events. If you are injured because of your participation in this study, the sponsor, without legal commitment, will compensate you without you having to prove that it is at fault. The sponsor will not compensate you where such injury results from any procedure carried out which is not in accordance with protocol for the study. Your right at law to claim compensation for injury where you can prove negligence is not affected.

Will my taking part in this study be kept confidential?

The interviews will be recorded digitally and transcribed verbatim by a professional company. No identifiable data will be transfer to the transcript company.

All the information you give during this study will be anonymised through the use of a code number unique to you. Your interview transcript will have this code number on thereby ensuring your confidentiality. A list of participants' age (years of experience), gender, and Job title against their code numbers will be recorded in a separate secure 'master coding sheet' to be held along with your consent form. In relation to personal identifiable data, the hard-copy transcripts will be kept with an indication of your years of experience, gender, occupation, and area of country; no names will be retained with the transcriptions.

Any audio recordings from the study and their related transcriptions will be identified by your individual code number only and will not be linked to your name in any way. Your data will be analysed by the research team of this study. Once analysed, the results of this study may be published in a scientific journal or presented at a research conference, possibly with literal quotes from yourself. However your identity and institution will be kept anonymous. In either case, your name will not be mentioned as part of the publication. The only times we may break confidentiality is if you tell us something that puts you or someone else's safety in danger.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at https://www.ncl.ac.uk/research/researchgovernance/ethics/gdpr/ and/or by contacting Mr Giles McCracken.

Version 5 15/11/2018

Certain individuals from Newcastle University, from regulatory authorities or from the NHS, may look at your research records to check the accuracy of the research study.

What will happen to the results of the research study?

When the study is completed, the researcher will process the information gathered and the results will be presented at scientific meetings and be published in journals.

Contacts

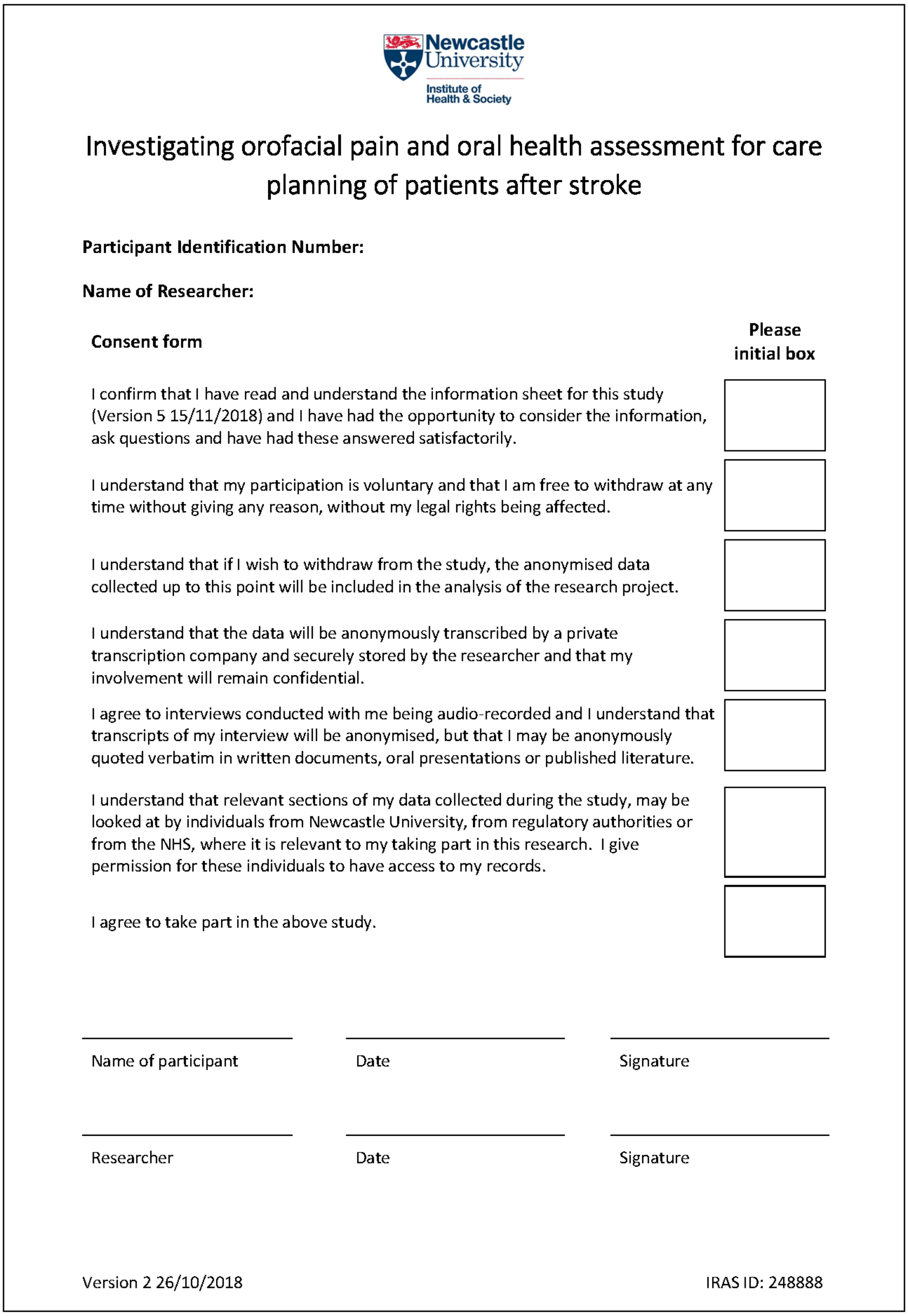
If you need to contact someone during the study, please use the contact information listed below:

Mr Giles McCracken	Mr Fahad BaHammam
Clinical Senior Lecturer	PhD student
giles.mccracken@ncl.ac.uk	f.a.s.bahammam1@ncl.ac.uk
0191 208 8194	01912087017

If you have any concerns or issues that you would like to raise about the study please contact the Chief Investigator, Mr Giles McCracken. If you remain unhappy and wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study. You can contact (Care of the) Head of Executive Office at Newcastle University, as follows:

(Care of the) Head of Executive Office
Newcastle University
King's Gate
Newcastle upon Tyne
NE1 7RU

Appendix J: Informed consent form used in the qualitative study



Newcastle University
Institute of Health & Society

Investigating orofacial pain and oral health assessment for care planning of patients after stroke

Participant Identification Number:

Name of Researcher:

Consent form	**Please initial box**
I confirm that I have read and understand the information sheet for this study (Version 5 15/11/2018) and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	☐
I understand that if I wish to withdraw from the study, the anonymised data collected up to this point will be included in the analysis of the research project.	☐
I understand that the data will be anonymously transcribed by a private transcription company and securely stored by the researcher and that my involvement will remain confidential.	☐
I agree to interviews conducted with me being audio-recorded and I understand that transcripts of my interview will be anonymised, but that I may be anonymously quoted verbatim in written documents, oral presentations or published literature.	☐
I understand that relevant sections of my data collected during the study, may be looked at by individuals from Newcastle University, from regulatory authorities or from the NHS, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
I agree to take part in the above study.	☐

Name of participant	Date	Signature
Researcher	Date	Signature

Version 2 26/10/2018 IRAS ID: 248888

Appendix K: Semi-structured interview topic guide used in the qualitative study

Newcastle University
Institute of Health & Society

Topic Guide of Semi-structured Interview (P)

I. **Introduction:**

- Interviewee consent – discuss interviewee's consent to be interviewed:
  - Brief description of the study aim, the parts of this interview, and the significant of interviewee's participation.
  - Any question or concern?
  - Check interviewee is happy to go ahead with interview
  - Go through consent form (emphasis confidentiality and indemnity)
  - Recording interview – check that interviewee is happy to go ahead

II. **Part 1: Experience, role and duties**

- What is your experience, role and duties regarding caring and providing health services for dependent patients after stroke?

III. **Part 2: Orofacial pain and oral health of patients after stroke**

- What does oral health mean to you in general?
- What does orofacial pain mean to you in general?
- What do you think about oral health in dependent patients after stroke?
  - How do oral health change in dependent patients after stoke? What are the causes?
  - What are oral health diseases/ conditions/ problems/ dependent patients after stroke has?
  - How changes in oral health affect dependent patients after stroke?
  - Do you think oral function change in dependent patients after stroke and how?
  - How changes in oral function affect dependent patients after stroke?
  - Do you think oral appearance change in dependent patients after stroke and how?
  - How changes in oral appearance affect dependent patients after stroke?
- What do you think about orofacial pain in dependent patients after stroke?
  - Do dependent patients after stroke have orofacial pain and what are the causes of the pain?
  - How orofacial pain affect dependent patients after stroke?

IV. **Part 3: Orofacial pain and oral health assessment for patients after stroke**

- What do you think about assessing and measuring oral health for dependent patients after stroke to guide care planning and why?
- What do you think about assessing and measuring orofacial pain for dependent patients after stroke to guide care planning and why?
- Do oral health and/ or orofacial pain assessed in your setting? Why? How?
    - Do you have an orofacial pain or oral health assessment instruments in your setting, do you use it and did you have previously trained to use it?
- Who should and can perform oral health and orofacial pain assessment to guide the care planning? Why?
- How many times should oral health and orofacial pain be measured? Why?
- What are the potential barriers for service providers to measure orofacial pain and oral health and how to overcome these barriers?
- What is the best strategy to implement oral health and orofacial pain assessment to guide care planning for dependent patients after stoke?
- What are the aspects of oral health that needs to be measured to guide care planning for dependent patients after stroke? Why?
- How orofacial pain could be measured for dependent patients after stroke to guide care planning?
- How assessing and measuring oral health and orofacial pain should guide care planning for dependent patient after stroke?

V. **Part 4: Previously developed assessment instrument(s)**

- The interviewee will be asked to read previously developed assessment instrument(s) and then the interviewee will be asked to evaluate the assessment instrument(s) according to following:
    - How well did you understand the assessment instrument(s) and is there any part of the instrument(s) that was not clear?
    - What do you think about this instrument(s)?
    - How the items of this instrument are relevant to dependent patients after stroke to guide care planning?
    - Is there any aspect of orofacial pain or oral health that need to be added to the instrument(s) to guide care planning?
    - How easily this instrument(s) could be implemented and used by services providers?

Version 7 18/03/2019

    - How do you think patients after stroke will receive this type of assessment?

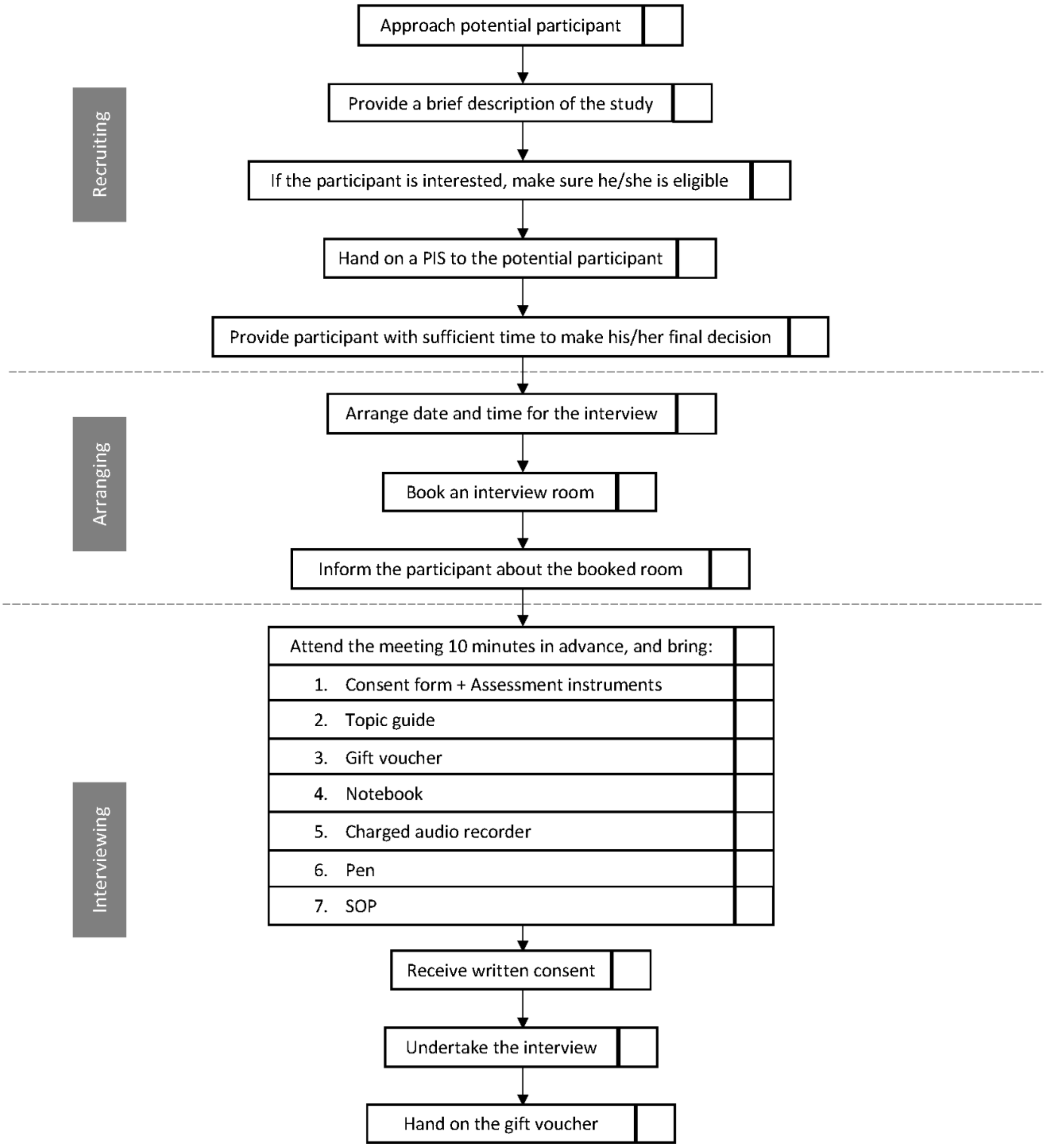
VI. Closing

- Is there anything I have not asked about that you think is important and would like to mention?
- Thank the interviewee for taking part

Version 7 18/03/2019

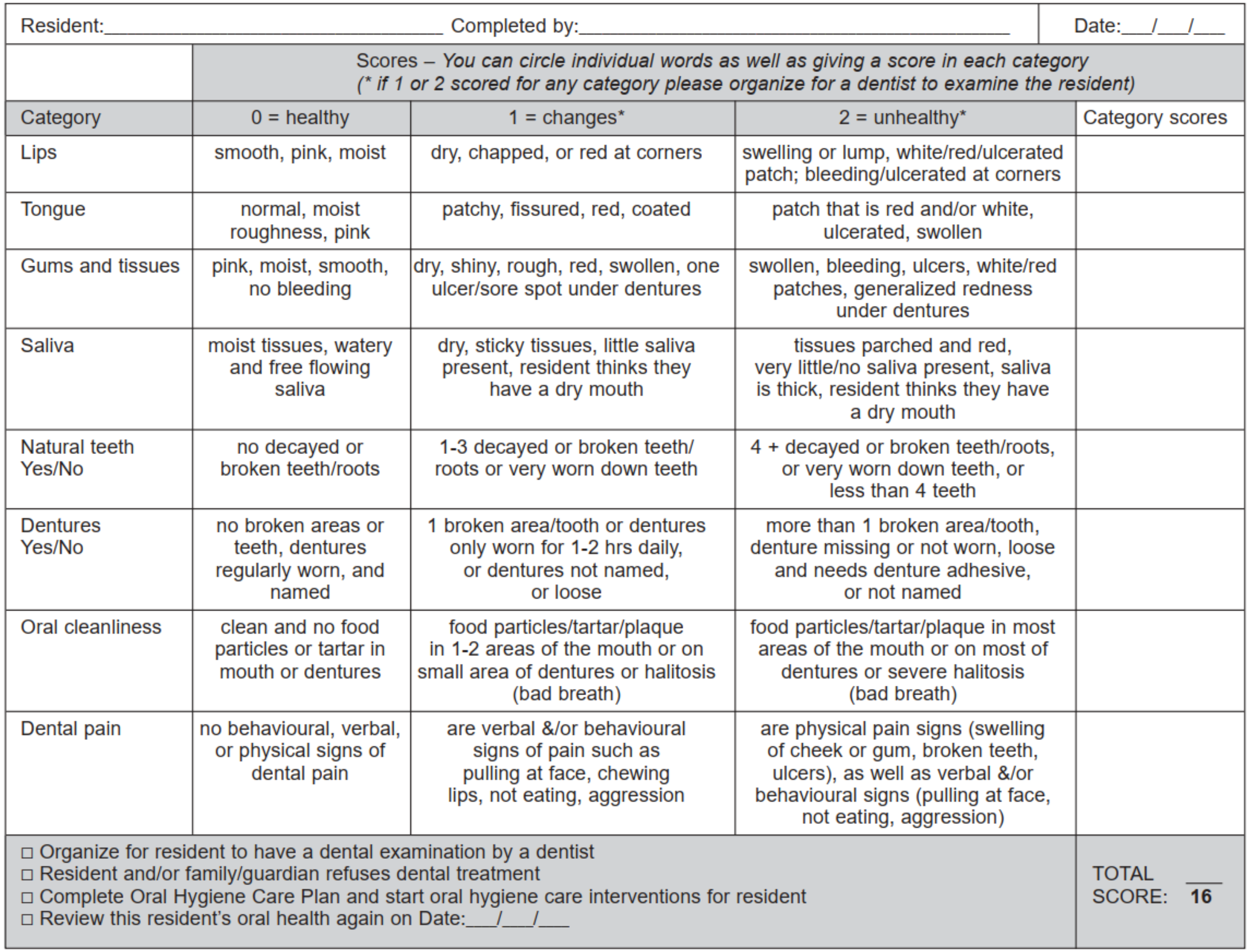
Appendix L: Standard operating procedure for the qualitative study

Standard operating procedure – qualitative interview study (P)



Appendix M: Oral health measurement instruments used as prompts during the interviews in the qualitative study

Measurement instrument 1: Oral Health Assessment Tool (OHAT) (Chalmers *et al.*, 2005)

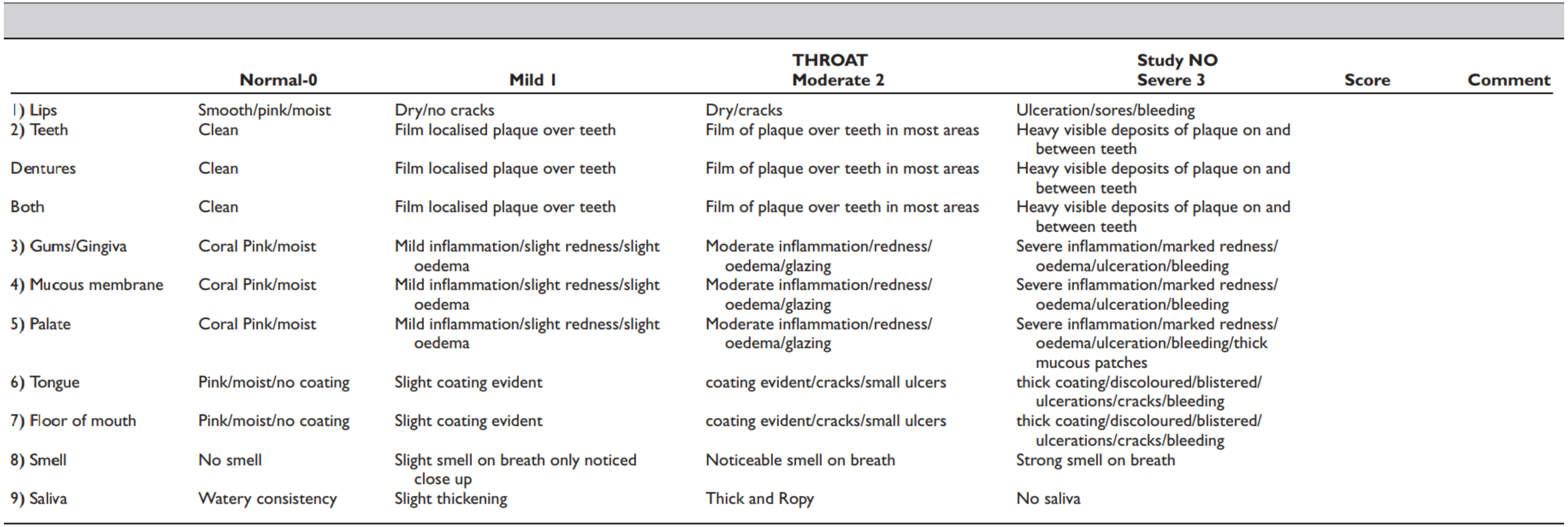


Resident:_________________________ Completed by:______________________________			Date:___/___/___	
	Scores – *You can circle individual words as well as giving a score in each category* *(* if 1 or 2 scored for any category please organize for a dentist to examine the resident)*			
Category	0 = healthy	1 = changes*	2 = unhealthy*	Category scores
Lips	smooth, pink, moist	dry, chapped, or red at corners	swelling or lump, white/red/ulcerated patch; bleeding/ulcerated at corners	
Tongue	normal, moist roughness, pink	patchy, fissured, red, coated	patch that is red and/or white, ulcerated, swollen	
Gums and tissues	pink, moist, smooth, no bleeding	dry, shiny, rough, red, swollen, one ulcer/sore spot under dentures	swollen, bleeding, ulcers, white/red patches, generalized redness under dentures	
Saliva	moist tissues, watery and free flowing saliva	dry, sticky tissues, little saliva present, resident thinks they have a dry mouth	tissues parched and red, very little/no saliva present, saliva is thick, resident thinks they have a dry mouth	
Natural teeth Yes/No	no decayed or broken teeth/roots	1-3 decayed or broken teeth/ roots or very worn down teeth	4 + decayed or broken teeth/roots, or very worn down teeth, or less than 4 teeth	
Dentures Yes/No	no broken areas or teeth, dentures regularly worn, and named	1 broken area/tooth or dentures only worn for 1-2 hrs daily, or dentures not named, or loose	more than 1 broken area/tooth, denture missing or not worn, loose and needs denture adhesive, or not named	
Oral cleanliness	clean and no food particles or tartar in mouth or dentures	food particles/tartar/plaque in 1-2 areas of the mouth or on small area of dentures or halitosis (bad breath)	food particles/tartar/plaque in most areas of the mouth or on most of dentures or severe halitosis (bad breath)	
Dental pain	no behavioural, verbal, or physical signs of dental pain	are verbal &/or behavioural signs of pain such as pulling at face, chewing lips, not eating, aggression	are physical pain signs (swelling of cheek or gum, broken teeth, ulcers), as well as verbal &/or behavioural signs (pulling at face, not eating, aggression)	
☐ Organize for resident to have a dental examination by a dentist ☐ Resident and/or family/guardian refuses dental treatment ☐ Complete Oral Hygiene Care Plan and start oral hygiene care interventions for resident ☐ Review this resident's oral health again on Date:___/___/___				TOTAL SCORE: ___ **16**

Measurement instrument 2: Revised Oral Assessment Guide (ROAG) (Andersson *et al.*, 2002)

Category	Method	Numerical and Descriptive Rating			Procedures
		1	2	3	
Voice	Converse with the patient	Normal	Deep or rasping	Difficulty talking or painful	Consult physician
Lips	Observe	Smooth and pink	Dry or cracked, and/or angular chelitis	Ulcerated or bleeding	Consult physician or dentist
Mucous membranes Dentures remove	Observe Use light and mouth mirror	Pink and moist	Dry and/or change in color, red, blue-red or white	Very red, or thick, white coating Blisters or ulceration with or without bleeding	Consult physician or dentist
Tongue	Observe Use light and mouth mirror	Pink, moist and papillae present	Dry, no papillae present or change in color, red or white	Very thick white coating Blisters or ulceration	Consult physician or dentist
Gums	Observe Use light and mouth mirror	Pink and firm	Edematous and/or red	Bleeding easily under finger pressure	Support with oral care Consult dentist or dental hygienist
Teeth/dentures	Observe Use light and mouth mirror	Clean, no debris	1) Plaque or debris in local areas 2) Decayed teeth or damage dentures	Plaque or debris generalized	1) Support with oral care 2) Consult dentist
Saliva	Slide a mouth mirror along the buccal mucosa	No friction between the mouth mirror and mucosa	Slightly increased friction, no tendency for the mirror to adhere the mucosa	Significantly increased friction, the mirror adhering or tending to adhere to the mucosa	Support with oral care Artificial saliva substitute
Swallow	Ask the patient to swallow Observe Ask the patient	Normal swallow	Some pain or difficulty on swallowing	Unable to swallow	Consult physician

Measurement instrument 3: The Holistic and Reliable Oral Assessment Tool (THROAT) (Dickinson *et al.*, 2001)



			THROAT	Study NO		
	Normal-0	**Mild 1**	**Moderate 2**	**Severe 3**	**Score**	**Comment**
1) Lips	Smooth/pink/moist	Dry/no cracks	Dry/cracks	Ulceration/sores/bleeding		
2) Teeth	Clean	Film localised plaque over teeth	Film of plaque over teeth in most areas	Heavy visible deposits of plaque on and between teeth		
Dentures	Clean	Film localised plaque over teeth	Film of plaque over teeth in most areas	Heavy visible deposits of plaque on and between teeth		
Both	Clean	Film localised plaque over teeth	Film of plaque over teeth in most areas	Heavy visible deposits of plaque on and between teeth		
3) Gums/Gingiva	Coral Pink/moist	Mild inflammation/slight redness/slight oedema	Moderate inflammation/redness/ oedema/glazing	Severe inflammation/marked redness/ oedema/ulceration/bleeding		
4) Mucous membrane	Coral Pink/moist	Mild inflammation/slight redness/slight oedema	Moderate inflammation/redness/ oedema/glazing	Severe inflammation/marked redness/ oedema/ulceration/bleeding		
5) Palate	Coral Pink/moist	Mild inflammation/slight redness/slight oedema	Moderate inflammation/redness/ oedema/glazing	Severe inflammation/marked redness/ oedema/ulceration/bleeding/thick mucous patches		
6) Tongue	Pink/moist/no coating	Slight coating evident	coating evident/cracks/small ulcers	thick coating/discoloured/blistered/ ulcerations/cracks/bleeding		
7) Floor of mouth	Pink/moist/no coating	Slight coating evident	coating evident/cracks/small ulcers	thick coating/discoloured/blistered/ ulcerations/cracks/bleeding		
8) Smell	No smell	Slight smell on breath only noticed close up	Noticeable smell on breath	Strong smell on breath		
9) Saliva	Watery consistency	Slight thickening	Thick and Ropy	No saliva		

References

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